

# Agenda – Petitions Committee

Meeting Venue:

Committee Room 1 – Senedd

Meeting date: 6 October 2015

Meeting time: 09.00

For further information contact:

Steve George – Committee Clerk

Kayleigh Driscoll – Deputy Clerk

0300 200 6565

[SeneddPetitions@assembly.wales](mailto:SeneddPetitions@assembly.wales)

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## 1 Introduction, apologies and substitutions

(Pages 1 – 18)

## 2 New petitions

2.1 P-04-650 Scrap Local Government Councillors' Salaries

(Pages 19 – 21)

2.2 P-04-652 Android and iOS – Welsh in the 21st Century

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### Health

3.1 P-04-408 Child and Adolescent Eating Disorder Service

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3.2 P-04-492 Diagnosis of autism in children

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**4 Motion under Standing Order 17.42 to resolve to exclude the public from the meeting for the following business:**

Item 5.

**5 Review of the National Assembly for Wales Petitions System**

(Pages 156 – 475)

Document is Restricted

# Agenda Item 2.1

## **P-04-650 Scrap Local Government Councillors' Salaries**

### **Petition wording:**

We call on the National Assembly for Wales to urge the Welsh Government to scrap Councillors' salaries. With cuts to public services and increases in council tax it is right that councillors share the burden by having their salaries scrapped and replaced with payments of reimbursement only, much like magistrates. This will help to make savings in expensive local democracy.

**Petition raised by:** Geraint Williams

**Date petition first considered by Committee:**

**Number of signatures:** 82 Online signatures



Eich cyf/Your ref P-04-650  
Ein cyf/Our ref LA -/00599/15

William Powell AM  
Assembly Member for Mid & West Wales  
Chair - Petitions Committee  
Ty Hywel  
Cardiff Bay  
Cardiff  
CF99 1NA

[SeneddPetitions@assembly.wales](mailto:SeneddPetitions@assembly.wales)

14 September 2015

Dear Bill,

Thank you for your letter of 12 August regarding the petition to scrap Local Government Councillor's Salaries.

In Wales, Councillors salaries are set by the Independent Remuneration Panel for Wales (the Panel). The Panel produces an Annual Report which sets out the type and level of payments that Local Authorities may or must make available to their members (councillors) and co-opted-members. In preparing its reports the Panel is required to take into account the likely financial impact of its decisions on the authority in question. In the 7 years since the Panel was established, it has developed a national framework which is applicable across Wales and allows control of the amount and number of payments to Councillors. The Panel is independent of both Welsh Government and Local Government

In the recent consultation on reforming Local Government (the White Paper, "Power to Local People") the Welsh Government recognised the tensions surrounding the role of a councillor between those that can devote all their time to it and those that have other commitments, and that no person should be out of pocket through serving their community. If Councillors were entitled to no remuneration for their time and efforts there is a danger that the democracy would be dominated by those who could afford to give their time for free. The future merger of Local Authorities will mean fewer councils and a reduction in the numbers of Councillors. This will result in a significant reduction in the costs of Local democracy.

Elected members of local authorities are there to represent the interest of local people, undertake the governance of local communities, and secure value-for-money public services for local tax-payers through effective scrutiny. Publicly funded remuneration is made available to encourage a range of willing and able people to stand for election.

This diversity is essential to ensure people feel they are appropriately represented.

Yours sincerely,

A handwritten signature in black ink, reading "Leighton Andrews". The signature is written in a cursive style. Below the signature is a long horizontal line that ends in an arrowhead pointing to the right.

**Leighton Andrews AC / AM**  
Y Gweinidog Gwasanaethau Cyhoeddus  
Minister for Public Services

# Agenda Item 2.2

## **P-04-652 Android and IOS, Welsh in the 21<sup>st</sup> Century**

### **Petition wording:**

We call on the National Assembly for Wales to urge the Welsh Government to work with Google and Apple to develop a Welsh language version of their operating systems.

### **Additional Information**

In recent years Welsh has had much greater representation in businesses, schools, universities, local councils and other public authorities; this had led to greater usage of Welsh in day to day activities for Welsh speakers, but that progress needs to be built on in order to stabilize and grow the number of speakers.

In this way, formal every day usage of Welsh could be seen as a success but informal every day usage of Welsh is the bigger problem. As for deep growth in language, knowledge isn't encouraged by formal usage. To deal with this issue it would be prudent to apply the same pressures and agreements presented to Microsoft on to Google and Apple to develop a Welsh language implementation of the android OS and iOS respectively.

Informal usage is proof of a living language.

**Petition raised by:** Merlyn Cooper

**Date petition first considered by Committee:** 6 October 2015

**Number of signatures:** 75 Online signatures



Eich cyf/Your ref: P-04-652  
Ein cyf/Our ref:FM -/00749/15

William Powell AM  
Chair - Petitions Committee  
Tŷ Hywel  
Cardiff Bay  
Cardiff  
CF99 1NA

[committeebusiness@Wales.gsi.gov.uk](mailto:committeebusiness@Wales.gsi.gov.uk)

14 September 2015

Dear William,

### **P-04-652 Android and iOS, Welsh in the 21st Century?**

I am writing in response to your letter of 26 August regarding the above petition from Merlyn Cooper asking the Welsh Government to work with Google and Apple to develop a Welsh language version of their operating systems Android and iOS respectively.

The Welsh Government wants to see more such services available in Welsh. Since the publication of the Welsh-language Technology and Digital Media Action Plan, meetings have been held with many of the international technology companies – including Apple and Google – where Welsh-language services, interfaces and systems were the focus of discussions.

Since these meetings were held, in the case of Apple, users of iOS8 can now select Welsh as their favourite language for third-party apps. This means that, in addition to the clock times and calendar dates, which were already available in earlier versions of iOS, multilingual apps downloaded from the App Store which include support for Welsh now display interfaces and notifications in Welsh by default. To take advantage of this feature, we have funded a Cardiff-based app localization agency to provide free Welsh language localizations to their international clients. This has resulted in a suite of high-profile apps now being available in Welsh.

This falls short of full localization of the iOS operating system. iOS8 currently supports around 40 languages, including variations of languages such as English, Spanish, Portuguese and Chinese. One difficulty is the lack of a Welsh speech-to-text infrastructure needed for Siri to be available in Welsh. To address this, we have funded work by Bangor University's Language Technology Unit through our Welsh-language Technology and Digital Media Fund to work towards a Welsh speech-to-text solution.

In the case of Google's Android, this is an open source operating system. It would be a challenging and big piece of work, but Android is available for anyone to translate into Welsh. We will continue to press for developments of Welsh-language services by companies such as Google as we did when Amazon opened their Kindle store to Welsh language titles and created a new e-book directory for Welsh-language titles on their website.

The point this petition makes about the importance of opportunities for informal use of Welsh such as with mobile phone and tablets is one we support. We will continue to try to motivate Apple and Google to offer more for Welsh speakers.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Carwyn Jones', written in a cursive style.

**CARWYN JONES**

# Agenda Item 3.1

## **P-04-408 Child and Adolescent Eating Disorder Service**

### **Petition wording:**

We call on the National Assembly for Wales to urge the Welsh Government to fund the Child and Adolescent Eating Disorder Service in Wales to the same degree as the Adult Eating Disorder Service in Wales.

It has come to my attention that there is a disparity in funding between Adult Services and Child and Adolescent Services as regards funding for Eating Disorder Treatment. At the present time Adult Eating Disorder Services receive £1 million per year from the Welsh Assembly, as well as 4 specialist trained provider groups.

Sadly research points to the fact that Eating Disorders, especially Anorexia Nervosa, are predominantly first experienced around puberty. Historically puberty was around 12-15, however, puberty is becoming younger and therefore statistics are beginning to show the prevalence of Anorexia Nervosa starting at younger ages is apparent. Bulimia Nervosa is generally a disease with an onset age of 18-25, however as with Anorexia this may differ from person to person. The fact that in both disorders, and indeed all diagnosable Eating Disorders, early intervention is the key to a quick recovery, therefore preventing long term financial implications for the WAG, makes this plea more pertinent.

I therefore implore the Assembly to consider this a priority for debate and to mend this disparity by giving equal finances and services to the Child and Adolescent Eating Disorder service in Wales as already given to Adult EDS.'

**Petition raised by:** Helen Missen

**Date petition first considered by Committee:** 17 July 2012

**Number of signatures:** 246



Eich cyf/Your ref P-04-408  
Ein cyf/Our ref MD/02050/15

William Powell AM  
Chair - Petitions Committee  
Ty Hywel  
Cardiff Bay  
Cardiff  
CF99 1NA

committeebusiness@Wales.gsi.gov.uk

24 July 2015

Dear William,

Thank you for your further letter of 3 July on behalf of the Petitions Committee in relation to petition p-04-408 about Child and Adolescent Eating Disorder Services (CAMHS ED).

You asked how my recent announcement of an extra £7.6m every year in mental health services for children and young people in Wales will improve the provision of services for children with eating disorders. The additional funding is not specifically for providing eating disorder services, though its impact will improve the provision of CAMHS for all children with mental health conditions, including eating disorders.

£2m of the funding will be devoted to developing services for those with neurodevelopmental conditions such as Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD). These currently make up a significant proportion of the referrals into specialist CAMHS services, though many of these young people do not subsequently require specialist CAMHS treatment. By ensuring these young people have their needs met elsewhere, this will free up specialist CAMHS staff time to devote to those with more complex mental illness, including eating disorders. Funding will also be available to improve provision at times of crisis and expand access to psychological therapies for young people. Both these initiatives will directly support young people with eating disorders, as will improving provision in primary care support services which will be able to support young people with very mild to moderate eating disorders.

I note the petitioner's continued concern regarding the funding disparity between adult and CAMHS services and our investment of £1m to improve specialist adult eating disorder provision. As I have stated previously, CAMHS has always seen the treatment of eating disorders as part of its core business and I used the 40% of CAMHS inpatient being treated for eating disorders merely illustratively. Of course, many more young people suffering an eating disorder will be treated by CAMHS as outpatients and the decision of health boards

earlier in the year to establish all-Wales coverage of CAMHS community intensive treatment teams will mean that many more young people will now be able to be treated in their community without recourse to hospitalisation.

With regard to the petitioner's comments regarding cost, I acknowledged the provision of CAMHS eating disorder services was inconsistent across Wales, with north Wales having a more developed service than south Wales. This is why I targeted the October 2013 announcement of an additional £250,000 a year towards the south, including southern Powys. It is not appropriate or helpful to compare the cost of CAMHS eating disorder provision with adult eating disorders for a number of reasons including the relevant size of the child and adult populations; differences in how clinical needs are met by both services; and the fact that eating disorders are often more enduring in adult life.

As the petitioner comments there is currently an NHS-led service change and development programme underway in CAMHS, which the Welsh Government is supporting, having asked Professor Dame Sue Bailey, chair of the Academy of Royal Medical Colleges, to provide advice and support. This programme is intended to make CAMHS more responsive to the needs of all its users, including those with an eating disorder.

I hope the committee finds my response helpful.

Best wishes,



**Mark Drakeford AC / AM**

Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services

**P-04-408 Child and Adolescent Eating Disorder Service – Petitioner to the Chair,  
10.09.15**

Dear Mr Powell

Mr Drakeford certainly writes a good letter! On reading it I almost believed that I should stop in my tracks and end all thought of argument.

I wonder if you and the committee are setting up a sweepstake as to how Mrs Missen will respond this time!

Part of me wanted to just copy and paste my last letter to you; as I'm not sure that much has been answered, except perhaps to applaud Mr Drakeford for providing specific monies for children with neurodevelopmental disorders such as Autism and ADHD.

If I were to split hairs some eating disorders are known to be biologically based brain disorders with genetic implications, much the same as Autism. Indeed, there is a grey area where the overlap of autism and anorexia is too close to define, and thus treatment of what is known as 'co morbidities' is within the cycle of treatment. Therefore, Mr Drakeford will be thrilled to know he has painted the picture well. Though his dot to dot approach has missed the colouring in of the issue: that more people die from an eating disorder than any other mental illness.

I think my real gripe is that he skirts the subject of the disparity between two areas of provision where money is concerned, in the only way a politician can. (No disrespect to you or the committee).

I agree the core treatment historically for CAMHS and AEDS has been and remains Eating Disorders.

Mr Drakeford seemingly apologises for his illustrative numbers of In Patients, but does not address the fact that AEDS have a tier 3 provision, within adult mental health services, specifically for Eating Disorders, which is where the £1 million is spent. He colours over the edges by implying that these are not in the community, which they are.

These are highly trained professionals specific to eating disorder treatment at that level which have been provided because of the Eating Disorder framework for Wales highlighting the void of care for anyone with an eating disorder in Wales, not just adults.

I'm fairly certain that the framework does not exclude people under the age of 18.

The fact is something had to be done for adults more quickly than for children; now unfortunately the reverse is in play.

Mr Drakeford alludes to North Wales having a robust and more stand alone service, excusing himself from providing funding for the whole of Wales.

Once again he has smudged the facts. The service he speaks of is an In Patient facility (the only one in Wales). Dr Glaze runs an exceptional CAMHS psychiatric unit with some specific beds for Eating disorders, which I know Mr Drakeford has visited and was apparently impressed by.

It is wonderful to have such a good clinician with a special interest in Eating Disorders, however, it is not the community service Mr Drakeford has implicated in his letter. I feel certain that Dr Glaze sees his patients in a clinic setting too, but this does not make it a community service.

If Dr Glaze and his team were provided with the same funding as South Wales were (should I be asking for the interest on top since 2013?) I am more than certain it would be of gold standard and wisely used for community treatment.

This really only leaves me the canvas to once again splash the colours that have not changed in my petition. The disparity of provision remains: children and adolescents with Eating Disorders are being sacrificed.

The adult services would (still) benefit better if Mr Drakeford really believed what he seemingly says. Provision at the first instance of an illness would mean less strain on an adult service.

To provide a specific and specialised tier 3 service (that being in the community and not in patient, which is tier 4) within CAMHS (or stand alone) for eating disorders would mean the cycle of these illnesses, in most instances, being reduced greatly in time and therefore resources would be saved.

Cynically, I also note that Mr Drakeford forgot to provide real numbers under the freedom of information act that I requested in the last letter, I wonder if they are not to his advantage?

I'm not sure if I look forward to the next instalment of the petition, though I am becoming older, wiser and still uncomfortable waiting for the outstanding resolution of the issue.

Helen Missen

## Extract from Gofal news page

### News

18 August 2015

Patients, professionals and politician call for renewed approach to eating disorders in Wales

A coalition of service users, families, carers, health professionals and politicians has today published their views on the key issues facing eating disorder services in Wales. Members of the National Assembly for Wales' Cross Party Group on Eating Disorders are calling on the Welsh Government to ensure that their voices are heard during work to refresh the Eating Disorders Framework for Wales.

Chaired by Bethan Jenkins AM, the cross party group provides a forum for people who use and deliver eating disorder services to discuss their views on policy, legislation and practice. Members have recently highlighted the need to refresh the Eating Disorders Framework for Wales, which was published back in 2009. Although progress has been made over the last six years, the group believes it is essential for the Welsh Government to consider the issues currently facing people with eating disorders and refresh their priorities accordingly.

During a series of cross party group meetings, members discussed the barriers that were preventing people with eating disorders from getting the support they needed – and their ideas for improving services in Wales. The resulting [document](#) was agreed by all members – including people who use and deliver services. It highlighted three overarching priorities:

- Review the Eating Disorders Framework for Wales
- Raise the profile of eating disorders in general mental health policy
- Improve attitudes and reduce stigma

The [document](#) then split the key issues into the following four areas:

**Early intervention: primary care and education:** Improving understanding, awareness and early identification in school and primary care – to ensure that people are able to access the treatment and support they need in a timely manner.

**Child and Adolescent Mental Health Services (CAMHS):** Improve the skills, relationships and transitions between CAMHS and specialist eating disorder services – to ensure children and young people get the best possible treatment and support.

**Skills and attitudes on general, mental health and paediatric wards:** Improving understanding and knowledge of eating disorders on general, mental health and paediatric wards – to reduce stigma and improve the patient experience.

**Support for people with ongoing experience of eating disorders:** Ensuring that people with an eating disorder receive high quality, recovery focused support – which builds self-esteem, enables people to live fulfilled lives and helps them to overcome barriers to housing, education and employment.

The [document](#) has been sent to Public Health Wales, which has been asked by the Welsh Government to refresh the framework. The Cross Party Group on Eating Disorders strongly believes that the refresh process must be open and transparent and provide people who use and deliver services with clear opportunities to share their views and contribute to the development of the new framework. Members understand that there will be a 30-day consultation period for people to submit their views and that further information will be made available on the Public Health Wales website.

**Chair of the Cross Party Group on Eating Disorders Bethan Jenkins AM said:**

“Although progress has been made, it is clear that much more can be done to improve eating disorder services and the experiences of patients in Wales. It is crucial that Welsh policy is refreshed and reflects the priorities of people using eating disorder services, as well as ensuring that our fantastic healthcare professionals do not face unnecessary barriers to delivering excellent care.

“I am very proud to publish this document, which represents the collective views of service users, family members, carers, health professionals and third sector representatives in Wales. With one voice, we are highlighting the key issues that we believe need to be addressed in the new Eating Disorders Framework for Wales. It is now crucial that the people who use and deliver eating disorder services are given the opportunity to contribute to the development of the new Framework and I encourage everyone with an interest to share their views.”

**James Downs, service user, volunteer and campaigner said:**

"Investing in expanding the recently-created specialist services based on a thorough review of the EDFW needs to be a key priority of the Welsh Government moving forward. Appropriately resourced services that keep people out of hospital and support people effectively in the community are desperately needed in Wales

now. I am looking forward to participating in the Welsh Government review alongside other service users, families and carers."

**Manon Lewis, service user, volunteer and campaigner said:**

"I am very grateful to have been given the opportunity to be involved in the development of the cross party group 'key issues' document as it addresses the challenges that I and many others have experienced. We need to improve knowledge and understanding throughout all parts of the health service so that people can get the appropriate support as soon as possible. We also need to challenge the stigma and discrimination that sufferers face and ensure that people with a longer term experience of eating disorders are supported to live fulfilled lives."

**Ewan Hilton, Chief Executive of mental health and wellbeing charity Gofal said:**

"It has been incredibly rewarding working with a group of people from a variety of backgrounds who are all deeply committed to improving eating disorder services and the experiences of people using them. We know that a good or poor experience of services can have a significant impact on people's lives and it is essential that the Welsh Government and Health Boards get this right."

**Dr Menna Jones, Chair of the Eating Disorders Sub-Group of the Wales Child and Adolescent Mental Health Services and Eating Disorders Planning Network:**

"Services for those with eating disorders have undergone a great deal of improvement since 2009 when the Eating Disorders Framework for Wales was first published. There remain key areas that need further development across the wide range of services that people with eating disorders come into contact with, and the work of the Cross Party Group on Eating Disorders has been valuable in enabling professionals to collaborate closely with service users and their families to identify priorities for ongoing work to ensure that sufferers and their families receive timely and appropriate support and treatment."

– See more at: <http://www.gofal.org.uk/news/2015/08/18/patients-professionals-and-politician-call-for-renewed-approach-to-eating-disorders-in-wales/#sthash.3XoCwYIQ.dpuf>

**P-04-408 Child and Adolescent Eating Disorder Service – Correspondence  
from the Petitioner to the Committee, 25.09.15**

Dear Kayleigh

As I am part of the cross party group and have been involved in the process that produced the document, I'm very happy for it to be used and therefore presented as evidence to support the ongoing petition.

I don't feel there is any need for me to comment further at this time.

Thanks for the information

Helen

# Agenda Item 3.2

## **P-04-492 Diagnosis of autism in children**

### **Petition wording:**

We call upon the National Assembly for Wales to urge the Welsh Government to:

- ensure timely diagnosis for children with Autism Spectrum Disorder [ASD], regardless of where they live, so that children with autism can be supported and lead fulfilled lives; and
- review implementation of and ensure compliance with the NICE guidelines on recognition, referral and diagnosis of children and young people on the autism spectrum as part of the Welsh Government's refresh of its ASD Strategic Action Plan.

### **Supporting information:**

Diagnosing can be a critical milestone for people with autism. For children, it can help ensure that the right support is put in place from an early age.

Diagnosing autism can be difficult because autism is complex condition that affects each person in a different way. We therefore support the view that a number of different specialists should be part of the process to ensure a correct diagnosis.

However a timely diagnosis is vital in order to minimise anxiety and stress for children with autism and their families. The Deputy Minister for Social Services supports this view and in response to a question from Rebecca Evans AM said: 'I fully recognise the importance of receiving a timely diagnosis.' We also know that early intervention for children with autism is crucial in their educational, emotional and social development and for their longer-term health.

While there are good examples of diagnostic and assessments services in Wales, we are very concerned that not everyone can access a timely diagnosis and that not every area is following the NICE guidelines on

recognition, referral and diagnosis of children and young people on the autism spectrum.

Our experience in Pembrokeshire has been particularly difficult, with some members of the branch waiting up to seven years for a diagnostic assessment. This lengthy wait for diagnosis is having a huge impact on families across Pembrokeshire.

We have tried on several occasions to engage with Hywel Dda Local Health Board. We have also met with local AMs Paul Davies and Angela Burns outlining our concerns. Paul Davies has written to Hywel Dda Health Board urging them to meet with the branch. We are still waiting for the Health Board to act on that request.

One of the branch members has 'waited over six years for my one son to get a diagnosis. Now I'm waiting for the other it's been about two years and it fills me with dread.'

We want to ensure timely diagnosis for all children with an Autism Spectrum Disorder across Wales so that they can be supported appropriately to lead fulfilled lives.

#### About autism

Autism is a lifelong developmental disability that affects the way a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all people with autism share three main areas of difficulty, their condition will affect them in different ways. The three main areas of difficulty are:

- Difficulty with social interaction. This includes recognising and understanding other people's feelings and managing their own. Not understanding how to interact with other people can make it hard to form friendships;
- Difficulty with social communication. This includes using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice; and

- Difficulty with social imagination. This includes the ability to understand and predict other people's intentions and behaviour and to imagine situations outside of their own routine. This can be accompanied by a narrow repetitive range of activities.

Some people with autism are able to live relatively independent lives but others may need a lifetime of specialist support. People with autism may also experience some form of sensory sensitivity or under-sensitivity, for example to sounds touch, tastes, smells, light or colours. Asperger syndrome is a form of autism.

Research has shown that 1 in 100 people have autism. By applying the 1 in 100 figure we estimate that over 30,000 people in Wales have autism. Together with their families, they make up over 100,000 people whose lives are touched by autism every single day.

#### About the NAS and Pembrokeshire Branch

The National Autistic Society Cymru [NAS Cymru] is Wales' only member-led charity for people affected by autism. The National Autistic Society was founded in 1962 by a group of parents who were passionate about ensuring a better future for their children. In Wales, since 1994, we have been providing local support, services and actively campaigning so that people with autism get to lead the life they choose.

NAS Cymru believes that the right support at the right time makes an enormous difference to the lives of those affected by autism and we are committed to ensuring that their voices are heard.

Across Wales we have over 900 members and 11 local branches including the one in Pembrokeshire. Launched on the 1st April 2011, the branch is for parents of children with autism to provide a network of support for people connected through autism living in Pembrokeshire and surrounding areas. The branch meets on a regular basis holding formal and informal events, as well as campaigning and fundraising locally.

**Petition raised by:** National Autistic Society Pembrokeshire Branch

**Date petition first considered by Committee:** 18 June 2013

**Number of signatures:** 902

Mark Drakeford AC / AM  
Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services



Llywodraeth Cymru  
Welsh Government

Eich cyf/Your ref P-04-492  
Ein cyf/Our ref MD/01349/15

William Powell AC / AM  
Chair - Petitions Committee  
Ty Hywel  
Cardiff Bay  
Cardiff  
CF99 1NA

13 May 2015

Dear William,

Thank you for your letter dated 23 April, asking me for my comments on correspondence you have received from the Pembrokeshire branch of the National Autistic Society Cymru in relation to Petition P-04-492 – Diagnosis of Autism in Children.

Taking each of their points in turn:

1. Louise Albert, deputy area manager for the National Autistic Society Cymru, is a member of the Autistic Spectrum Disorder (ASD) diagnostic task and finish group. The Pembrokeshire branch will be able to provide information to the group via her representation, as appropriate.
2. Grant funding has been allocated this year to undertake a mapping exercise to gather information on current diagnosis across Wales and undertake a clinical audit. The findings will help shape the task and finish group's recommendations on how diagnostic services can be improved and waiting times reduced.
3. The task and finish group will produce a report with recommendations for my consideration. At that time I will make a final decision on whether the report will be made public, although I do not anticipate there being any barriers to its publication.

Best wishes,

Mark.

Mark Drakeford AC / AM  
Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services

Bae Caerdydd • Cardiff Bay

Cardiff  
CF99 1NA  
Pack Page 38

Wedi'i argraffu ar bapur wedi'i ailgylchu (100%)

English Enquiry Line 0300 0603300  
Llinell Ymholiadau Cymraeg 0300 0604400  
Correspondence.Mark.Drakeford@wales.gsi.gov.uk

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cyf:  
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Date/Dyddiad: 1<sup>st</sup> May 2015  
Tel/ffôn: 01443 744803  
Fax/ffacs: 01443 744888  
Email/ebost: Allison.williams4@wales.nhs.uk  
Dept/adran: Chair & Chief Executive

Mr William Powell AM  
Chair, Petitions Committee  
National Assembly for Wales  
Cardiff Bay  
Cardiff  
CF99 1NA

Dear Mr Powell

### **Petition: P-04-492 Diagnosis of Autism in Children**

#### **Cwm Taf University Health Board Autistic Spectrum Disorder Waiting Times May 2013**

The term 'Autistic Spectrum Disorder' (ASD) used throughout this response includes all diagnoses covered by the condition including, for example, Autism, Kanners Autism, Asperger's Syndrome.

ASD is defined as "...a lifelong developmental disability affecting social and communication skills. People with the disability can also have accompanying learning disabilities but, whatever their general level of intelligence, everyone with the condition shares a difficulty in making sense of the world... The degree to which people with autistic spectrum disorder are affected varies, but all those affected have impairments in social interaction, social communication and imagination. This is known as the triad of impairments."

#### **Context of ASD Diagnosis in Children and Young People**

The need for a clear diagnostic pathway was outlined in the ASD Strategic Action Plan for Wales which was published in April 2008 and in the local ASD Action Plan published in 2009.

The last few years have seen significant development in services since the launch of the national strategy which has raised awareness and understanding of autism and, as a result, more and more children are being identified earlier, particularly around the time they are about to commence school.

In September 2011 National Institute for Clinical Excellence (NICE) published a guideline for the recognition, referral and diagnosis of children and young people on the autism spectrum.

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**Return Address: Ynysmeurig House, Unit 3, Navigation Park, Abercynon, CF45 4SN**

This requires a clear pathway to be in place which was in line with identified local need and had been included in local action plans. Mapping of services had found that diagnosis of ASD was inconsistent, lengthy and geographically variable for children and young people across Cwm Taf and indeed the whole of Wales.

NICE and best practice indicate that diagnosis of ASD should include assessments from a range of staff including Child and Adolescent Mental Health Service (CAMHS), Paediatrics, Speech and Language Therapy (SLT), Occupational Therapy (OT) and Educational or Clinical Psychology. However, referral for assessment is reliant on a variety of other front-line professionals such as Health Visitors, Teachers, etc identifying, referring and informing the assessment process for children and young people.

In order to support and strengthen assessment across all services within Cwm Taf and to ensure consistency, 3Di training has been provided to approximately 20 professionals inclusive of Therapies, Paediatrics, CAMHS and Educational Psychology. We have also provided ADOS training for 23 staff in February and March 2014. ADOS and 3Di are evidence based assessment tools recommended by NICE and used locally to assess and diagnose children and young people with ASD.

ASD is not normally diagnosed at a very young age even though parents may have had concerns for some time and this is for a range of reasons:

- Problems that the child is displaying and presenting with are rarely specific to autism and therefore professionals need to ensure that they are not misdiagnosing. It would be inappropriate for non-specialists to make a diagnosis and they often do not want to 'label' the child or worry the parents unnecessarily until they have ruled out other possible diagnoses. What sometimes appears to be an apparent reluctance to diagnose autism is actually the professionals need to ensure that they get the diagnosis right.
- ASD is a complex condition which is demonstrated by the wide spectrum of difficulties that may be experienced from those at the severest end to those who are high-functioning and / or only have mild autistic traits. The child / young person should be assessed by a range of multi-disciplinary professionals (as highlighted above) in order to reach a diagnosis which will include observations of their behaviour and in order to be thorough this can be a very timely process. Clearly, the diagnosis of ASD is not just the responsibility of health as we rely on professionals from a variety of other settings, eg schools, to identify and assess the needs of these children and young people.
- Some aspects of ASD may only become more apparent as the child gets older and the extent of their problems may not become clear until, for example, they enter new social situations such as school.

Unfortunately the diagnostic process for ASD can be lengthy but this should get shorter as awareness of ASD is increased amongst the public and professionals.

### **Waiting Times across Cwm Taf**

Since the creation of the new Health Boards in Wales it is recognised that service delivery in the previous NHS Trusts varied. As part of our work locally to review the assessment and diagnostic process it has been highlighted that different services took the lead in different areas.

**Currently, waiting times for commencement of Community Paediatric and CAMHS assessment (from receipt of referral to initial assessment) are approximately 60 weeks.** Within this approximate waiting time please be aware that the final diagnosis will also be dependant on a number of assessments and provision of information via other frontline professionals such as:

- Occupational therapy
- Speech and language Therapy
- Educational Psychology etc

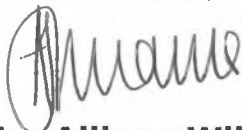
The ongoing work looking to implement the South Wales Programme and redesign local services is looking to review all our processes and to determine how we can ensure more equitable service provision across our local communities jointly with our partners.

Key staff from Cwm Taf University Health Board are also represented on the National ASD Assessment and Diagnosis steering group looking at a National position to improve and support families awaiting assessment and diagnosis of their children's needs.

For Adults who are referred for assessment and diagnosis of ASD Cwm Taf Health Board are funded to provide a diagnostic and advice service for Autistic Spectrum Disorder. This is led by a Consultant Psychiatrist and Psychologist.

There are currently no waiting time issues for adult services across the Cwm Taf University Health Board area.

Yours sincerely



**Mrs Allison Williams**  
**Chief Executive/Prif Weithredydd**





**GIG**  
CYMRU  
**NHS**  
WALES

Bwrdd Iechyd Prifysgol  
Caerdydd a'r Fro  
Cardiff and Vale  
University Health Board

**Ysbyty Athrofaol Cymru**  
**University Hospital of Wales**  
**UHB Headquarters**  
Heath Park  
Cardiff, CF14 4XW

Parc Y Mynydd Bychan  
Caerdydd, CF14 4XW

Eich cyf/Your ref: P-04-492  
Eiri cyf/Our ref: AC-ns-05-4778  
Welsh Health Telephone Network:  
Direct Line/Llinell uniongychol: 02920 745681

**Professor Adam Cairns**  
**Chief Executive**

07 May 2015

William Powell AC/AM  
Chair  
Petitions Committee  
National Assembly Wales  
Cardiff Bay  
Cardiff  
CF99 1NA

Dear William

**Re Petition P-04-492 Diagnosis of Autism in Children**

I write in response to your letter received on 23 April 2015 to confirm that I support that children should have access to timely diagnostic processes wherever they live.

In Cardiff and the Vale we operate a Social and Communication Assessment Pathway (SCAP) in order to provide a clear diagnostic process for children and their families. This is a multidisciplinary and multiagency process, ensuring that children are assessed by educational and health professionals prior to a decision being made with regards to diagnosis.

We aim to complete the process in line with NICE guidelines. However this is not always possible for a variety of reasons. It may be that a child's developmental profile means that a clear diagnosis is not always possible within the timescale, as signs and symptoms emerge. In some cases Autism may also be associated with other medical conditions. In complex cases the time to diagnosis may have to be extended in order to gather all relevant information before a diagnosis can be made.

I hope this is helpful

Yours sincerely

**Ruth Walker**  
**Acting Chief Executive, on behalf of**  
**Professor Adam Cairns**  
**Chief Executive**





Bwrdd Iechyd Prifysgol  
Betsi Cadwaladr  
University Health Board

Mr William Powell AC / AM  
Chair of Petitions Committee  
National Assembly for Wales  
Cardiff Bay  
Cardiff  
CF99 1NA

**Ein cyf / Our ref:** TP/BH/3952/445

**Eich cyf / Your ref:** P-04-492

**☎:** 01248 384910

**Gofynnwch am / Ask for:** Linda Hughes

**E-bost / Email:** [linda.hughes@wales.nhs.uk](mailto:linda.hughes@wales.nhs.uk)

**Dyddiad / Date:** 15 May 2015

Dear Mr Powell

**PETITION: P-04-492 DIAGNOSIS OF AUTISM IN CHILDREN**

Thank you for asking me to comment on this Petition. It is of course a concern that Betsi Cadwaladr University Health Board (BCUHB) are not currently able to ensure timely diagnosis for children with Autism Spectrum Disorder nor are we able to fully comply in all areas with NICE Guidelines.

It appears over the last few years that the demand for ASD assessment has significantly increased. It is the view of our Clinicians that this is partly due to an overall lowering threshold for diagnosis and also greater awareness within the broader children's services of Autism Spectrum Disorder.

In BCUHB there is significant variation in waiting times for diagnosis. Our shortest waits are in Conwy, where the waiting times are 21 weeks and our longest waiting times are in North East Wales where waiting times for an Autism Spectrum Disorder assessment are 129 weeks.

It would be helpful to have policy guidance on the relative contributions of Community Child Health/Community Paediatrics and on the other hand Child and Adolescent Mental Health Services.

As demand has increased for urgent mental health assessments and also the necessity of complying with the Mental Health Measure there has been a tendency for Autism Spectrum Disorder assessments to be seen as routine and non-urgent work. Waiting times for Autism Spectrum Disorder assessments, particularly when led by CAMHS services, have therefore been adversely affected by our efforts to meet the urgent demands upon our CAMHS services.

There is significant variation in the region in terms of the contribution of Speech and Language Therapy.



Bwrdd Iechyd Prifysgol  
Betsi Cadwaladr  
University Health Board

A clear focus on the NICE guidelines paying attention to the role of Speech and Language Therapy, timely diagnosis and the interface between CAMHS service and Community Child Health would therefore be helpful.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'T. Purt', written over a light blue horizontal line.

**Prof Trevor Purt**  
**Chief Executive**

**Vivienne Harpwood, Cadeirydd / Chair**  
Ffon / Phone: 01874 615971  
E-bost / Email: [Vivienne.Harpwood@wales.nhs.uk](mailto:Vivienne.Harpwood@wales.nhs.uk)



**GIG**  
CYMRU  
**NHS**  
WALES

Bwrdd Iechyd  
Addysgu Powys  
Powys Teaching  
Health Board

**Carol Shillabeer, Y Prif Weithredwr /  
Chief Executive**  
Ffon / Phone: 01874 615980  
E-bost / Email: [carol.shillabeer2@wales.nhs.uk](mailto:carol.shillabeer2@wales.nhs.uk)

26 May 2015

Mr William Powell AM  
Chair  
Petitions Committee  
National Assembly for Wales  
Cardiff Bay  
Cardiff  
CF99 1NA

Dear Mr Powell

**RE: ASD WAITING TIMES**

Thank you for your letter requesting information relating to the Powys service.

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- 2011/12 – 18 weeks (9 week average wait)
- 2012/13 – 17 weeks 3 days (8 week average wait)
- 2013/14 – 21 weeks (7 week average wait)
- 2014/15 (up to November 2014) – 16 weeks (5 week average wait)

The Powys SCATs are responsible for the assessment and diagnosis of children and young people up to and including the age of 18 years with social and/or communication difficulties. The pathway has been developed in accordance with The National Institute for Health and Clinical Excellence (NICE) Guidelines for *Autism: Recognition, Referral and Diagnosis of Children and Young People on the Autism Spectrum* published September 2011 (please see attached SCAT Terms of Reference inclusive of pathway

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Aberhonddu, Powys LD3 7HR  
Ffôn: 01874 711661



Corporate Hub (South)  
Neuadd Brycheiniog, Cambrian Way,  
Brecon, Powys LD3 7HR  
Tel: 01874 711661

Rydym yn croesawu gohebiaeth Gymraeg  
Bwrdd Iechyd Addysgu Powys yw enw gweithredd Bwrdd Iechyd Lleol  
Addysgu Powys



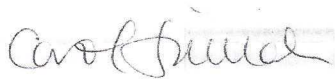
We welcome correspondence in Welsh  
Powys Teaching Health Board is the operational name of  
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for information). Much work has been progressed in the past four years to review processes as well as develop and implement the pathway and ultimately reduce waiting times.

With regards to adult assessments, please find attached Powys Teaching Health Board's progress as at November 2014, in accordance with the All Wales ASD Clinical Network Standards, drawn from NICE Guidelines *Autism Recognition, Referral, Diagnosis and Management of Adults on the Autism Spectrum* published June 2012. There are currently 26 adults waiting for an ASD assessment and the longest wait is 7 months from the date the referral was accepted.

I hope this information is helpful.

Yours sincerely



**Carol Shillabeer**  
**Chief Executive**

Encs.



## SOCIAL COMMUNICATION & ASSESSMENT TEAMS (SCAT) – POWYS

### TERMS OF REFERENCE

#### PURPOSE

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- 3Di – (Developmental, Dimensional, and Diagnostic Interview) comprising a computer based interview of the parents accompanied by the questionnaire outcome. (Not suitable for children under 3 years)
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On conclusion of the assessment process, feedback is provided to the parents and if appropriate, the child/young person being assessed in a formal meeting as appropriate. This will include a SCAT team representative and the professional who requested the assessment. A school representative and other professionals involved with the child/young person will be invited to the meeting. A referral/s to other services can be made as appropriate. A follow up meeting will also be offered to parents within six weeks of the feedback meeting should they wish to discuss conclusions further. SCAT will cease involvement with the child immediately after the feedback meeting or follow up meeting if parents opt to attend.

The work undertaken by SCAT is vital in supporting the objectives outlined in the Welsh Government's (WG) Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales (2008). The team will provide a forum for multi-agency and multi-disciplinary collaborative working between Powys Teaching Health Board and Powys County Council.

The teams will link to the with Powys ASD Stakeholder Group who are responsible for implementing the national plan at a local level as per the Powys ASD Action Plan 2011-14.



## **MEMBERSHIP**

Membership of the SCA Teams will comprise the following representation and collectively have experience and training in the diagnosis of ASD. See Appendix 2.

- Chair – ASD Co-ordinator for POWYS
- Consultant Paediatrician
- Child & Adolescent Mental Health Service (CAMHS)
- Educational Psychology
- Children's Speech and Language Therapy
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- Specialist Nursing for Children with Learning Disabilities
- Social Care - Children with Disabilities Team (CWD)

## **CIRCULATION OF MINUTES & OTHER DOCUMENTATION TO:**

- Social Communication & Assessment Teams
- Powys Teaching Health Board (THB) Clinical Director for Women & Children's Services

## **AIM OF THE TEAM**

The aim of the Powys Social Communication and Assessment Teams is to assess social and communication difficulties of a child or young person in whom significant concerns have been raised.

## **OBJECTIVES OF THE TEAM**

1. To act as a forum within Powys for formal ASD assessments of children and young people up to and including the age of 18 years.
2. To discuss new children for whom a SCAT assessment has been requested and confirm if eligibility criteria has been met in order to proceed with assessment.
3. Undertake formal assessment of a child or young person as illustrated and in accordance with the approved SCAT pathway. See Appendix 1.
4. To use evidence based ASD assessment tools in the SCAT assessment process.
5. To ensure high-quality assessment outcomes for all children and young people with an ASD in Powys in accordance with the All Wales Strategic Action Plan 2008.
6. To undertake assessments in accordance with The National Institute for Health and Clinical Excellence (NICE) guidelines for 'Autism: recognition, referral and diagnosis in children and young people' published 28<sup>th</sup> September 2011.
7. To take all appropriate steps to ensure that assessments of ASD within Powys are inclusive and so do not discriminate on the grounds of ethnic origin, Welsh language, gender, age, disability or sexual orientation.
8. To signpost individuals to other agencies and professionals who may be able to provide support for issues identified during the assessment.
9. To establish and maintain links with key stakeholders from statutory and voluntary organisations and the Powys ASD Stakeholder Group and Local Resource Solution Panels.
10. To liaise with the Health, Education and Social Care Services when appropriate during the SCAT process in regards to the complex needs of children with ASD and their families
11. To maintain links with the Powys Children and Young People's Partnership, Health, Social Care and Well Being Partnership and teaching Health Board.



## FREQUENCY OF MEETINGS

- Meetings will be held monthly for the North and South teams with the exception of August
- Meetings will be chaired by the ASD Co-ordinator for Powys
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- A joint North and South annual meeting will be scheduled to review processes or on an ad-hoc basis as required

## ROLES & RESPONSIBILITIES

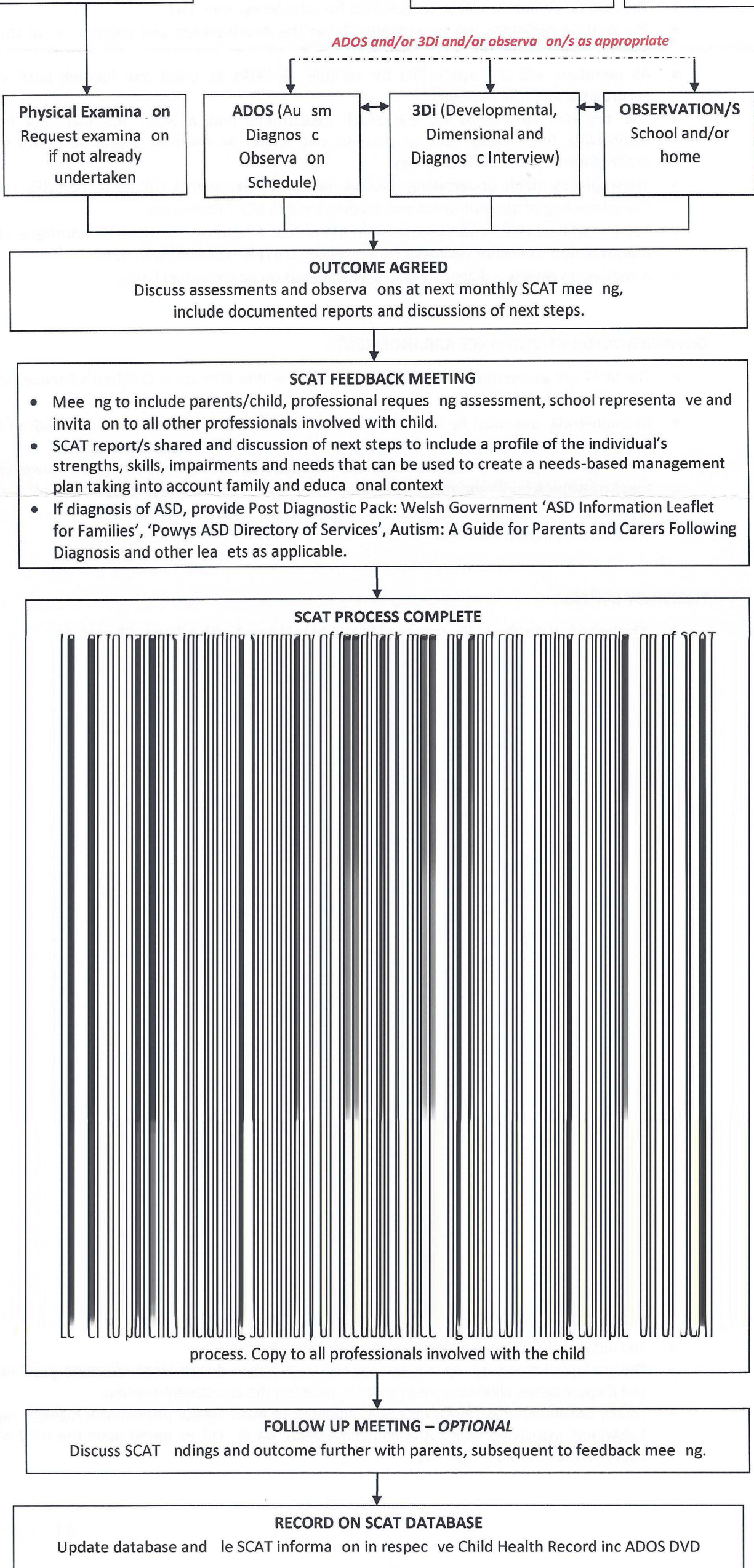
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- Team members must undertake a minimum of four of each assessment tool during a 12 month period to ensure skills and competences are relevant and up to date.
- A request to review a diagnosis will be considered on an individual basis.

## ORGANISATIONAL GOVERNANCE ARRANGEMENTS

- The SCAT are accountable to the Clinical Director within Women & Children's Services at Powys teaching Health Board
- Recommendations must be reported to the Clinical Director within Women & Children's Services at Powys teaching Health Board and the Powys ASD Stakeholder Group.
- Meetings can proceed regardless of the numbers of professionals present however there must be a minimum of 3 professionals to enable decisions regarding acceptance of new cases to be made. Opportunities for members to respond outside of the meeting will be co-ordinated via email.

## ELIGIBILITY CRITERIA

- The individual resides in the county of Powys or registered with a Powys GP practice.
- The individual is 18 years or younger at time of the request.
- The professional requesting the assessment must obtain documented informed parental and if appropriate, child consent in order to progress the assessment process.
- Clearly documented evidence by a SCAT member or other health professional highlighting behaviours associated with social and communication difficulties based upon the triad of impairments in a range of settings.



**Vivienne Harpwood, Cadeirydd / Chair**  
Ffon / Phone: 01874 615971  
E-bost / Email: [Vivienne.Harpwood@wales.nhs.uk](mailto:Vivienne.Harpwood@wales.nhs.uk)



**GIG**  
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**Carol Shillabeer, Y Prif Weithredwr /  
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Ffon / Phone: 01874 615980  
E-bost / Email: [carol.shillabeer2@wales.nhs.uk](mailto:carol.shillabeer2@wales.nhs.uk)

26 May 2015

Mr William Powell AM  
Chair  
Petitions Committee  
National Assembly for Wales  
Cardiff Bay  
Cardiff  
CF99 1NA

Dear Mr Powell

**RE: ASD WAITING TIMES**

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Rydym yn croesawu gohebiaeth Gymraeg  
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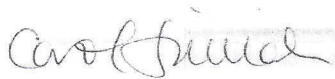
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I hope this information is helpful.

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**Carol Shillabeer**  
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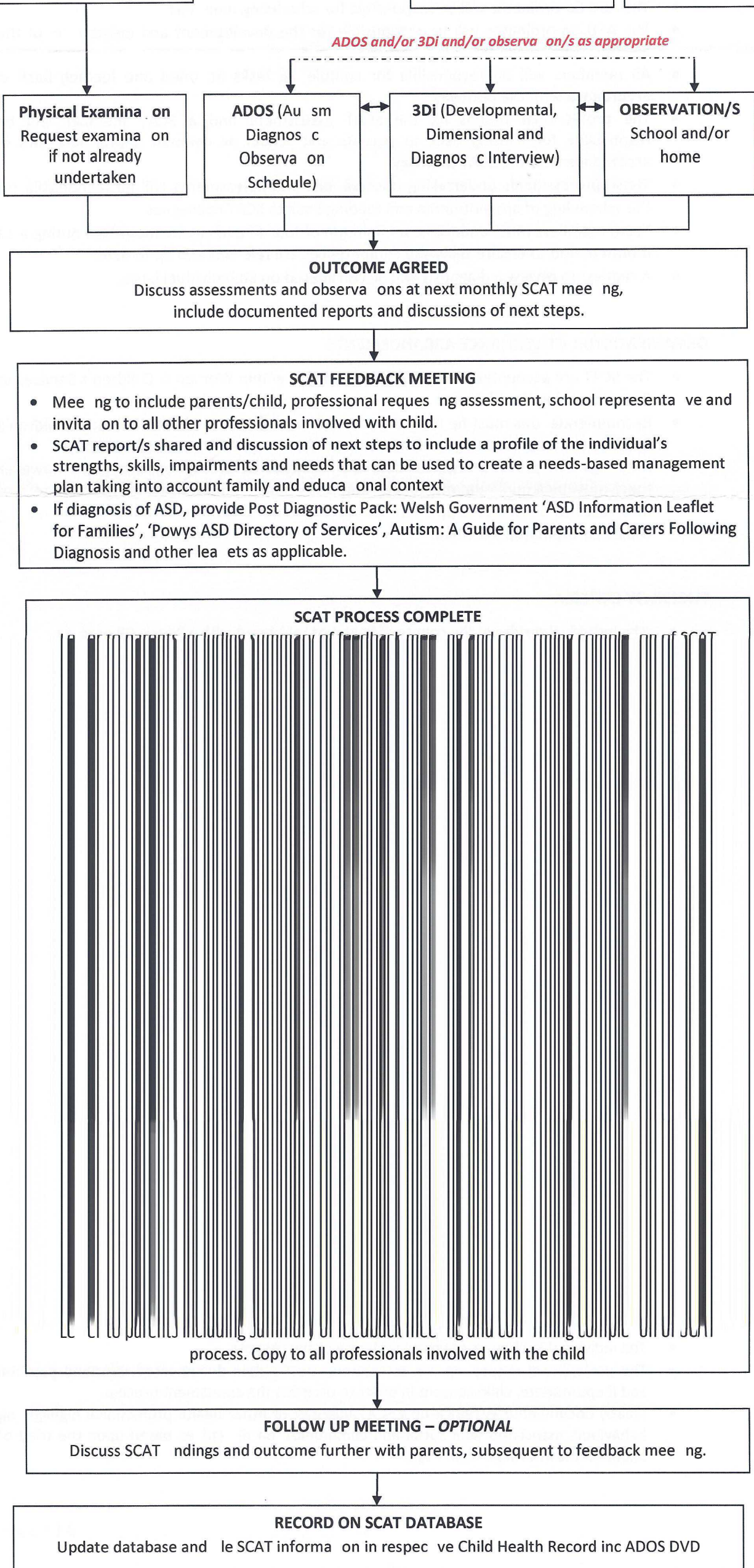
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**P-04-492 Diagnosis of autism in children – Correspondence from the  
Petitioner to the Committee, 30.09.15**

Hi Kayleigh

With apologies for missing the midday deadline, my only comment on the responses is the request from Trevor Purt, Chief Executive of Betsi Cadwaladr Health Board, and whether Welsh Government could provide this to all of the Health Boards? Mr Purt's comments are:

'It would be helpful to have policy guidance on the relative contributions of Community Child Health/Community Paediatrics and on the other hand Child and Adolescent Mental Health Services.'

Many thanks

Meleri

# Agenda Item 3.3

## **P-04-532 Improving specialised neuromuscular services in Wales**

### **Petition wording:**

We call on the National Assembly for Wales to urge the Welsh Government to ensure that Health Boards implement the investment proposed by the Welsh Neuromuscular Network Vision Document for improving specialised neuromuscular services in Wales.

### **Additional Information:**

The Welsh Neuromuscular Network is recommending the following priority developments: 1. Increase in Family Care Advisors and support. 2. Specialist adult neuromuscular physiotherapists. 3. Appointment of consultant in adult neuromuscular disease. 4. Increase in clinical psychology. 5. An equipment budget to enable minor purchases and lease arrangements.

**Petition raised by:** Muscular Dystrophy Campaign

**Date Petition first considered by Committee:** 4 February 2014



**Private & Confidential**

Mr William Powell AC / AM  
Chair of Petitions Committee  
National Assembly for Wales  
Cardiff Bay  
Cardiff  
CF99 1NA

**Ein cyf / Our ref:** TP/AM/3953/439

**Eich cyf / Your ref:** P-04-532

**☎:** 01248 384910

**Gofynnwch am / Ask for:** Linda Hughes

**E-bost / Email:** [linda.hughes@wales.nhs.uk](mailto:linda.hughes@wales.nhs.uk)

**Dyddiad / Date:** 13 May 2015

Dear Mr Powell

**P-04-523 Improving Specialised Neuromuscular Services in Wales**

Thank you for your letter dated 23 April 2015 regarding the Petition received from the Muscular Dystrophy Campaign and asking for our views on the Petition.

The Welsh Neuromuscular Network has recommended a number of priority developments as highlighted below:

**1. Increase in Family Care Advisors and Support**

It is agreed that these posts can benefit patient and family by acting as advocates and can help patients and families through health, social and voluntary care services to ensure optimum treatment and experience as highlighted.

**2. Specialist Adult Neuromuscular Physiotherapists**

North Wales does not specifically have a Specialist Adult Neuromuscular Physiotherapist. We do however have Specialist Neurological Physiotherapists who have the appropriate training and skills to manage adults with neuromuscular conditions. Physiotherapy services would be in support of a Neurological Physiotherapist who would work with people with neuromuscular conditions to participate in further training specific to neuromuscular conditions and to continually improve the quality and efficiency of services provided.

Physiotherapy intervention for people with neuromuscular conditions involves developing a programme alongside the person with a neuromuscular condition, for example:

- to minimise the development of contractures and postural deformities through a programme of positioning, stretches and exercises;
- to anticipate and minimise any secondary physical complications through the above to include seating;
- to identify and prescribe aids and equipment, including positional equipment, and working with wheelchair services on seating equipment;
- to advise on moving and handling;

- to monitor respiratory function and advise on techniques to assist with breathing exercises and methods of clearing secretions.

The above therapeutic interventions could be carried out safely and effectively by neurologically trained Physiotherapists; which is a specialism within Physiotherapy. Depending on the clinical presentation, Physiotherapists with different specialisms have the most appropriate knowledge and skills to treat the person (for example, a Physiotherapist Specialist in respiratory care if the current problem is a chest infection). It is important that there is a Specialist Neurological Physiotherapist with the awareness and knowledge of neuromuscular conditions involved in the care of people with neuromuscular conditions to ensure that these people receive maximally effective therapy. The Neuromuscular Specialist Physiotherapist would have a more in depth knowledge of those conditions, (such as muscular dystrophy), increased awareness and knowledge about the amount/intensity of exercise appropriate for these conditions. Treatment techniques are the same as other neurological conditions; stretches, positioning, exercise but knowledge of suitable intensity is an acquired skill. The evidence base is less than supportive currently to the profession in this remit, hence each case is considered individually and experience is invaluable.

Our Neurological Physiotherapists will hold the core principles of treatment, and if treating this group of patients they are professionally required to develop the necessary additional knowledge required of the condition. They would be supported by the organisation in this regard.

It would not be effective use of time to employ one Physiotherapist to treat adult neuromuscular conditions in North Wales given the low volumes and excessive travel time, however we would wholly support additional training/teaching/workshops for professionals working with people with this group of conditions to increase knowledge and skills to highlight any differences in therapeutic management to optimise the quality of the service provided, as suggested.

### **3. Appointment of Consultant in Adult Neuromuscular Disease**

Consultants specialising in neuromuscular disease could provide leadership within multidisciplinary teams and focus on education and support for partners and also lead the development and implementation of care pathways. An assessment would need to be undertaken to determine whether the appointment of a consultant in adult neuromuscular disease would be the best way forward.

### **4. Increase in Clinical Psychology**

We recognise the valuable contribution made by Clinical Psychologist to the care provided to both adults and children with neuromuscular disease. We employ over a 100 qualified Clinical Psychologists in the Health Board with a range of expertise and are working hard to meet the needs of patients in a timely and appropriate way.



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Betsi Cadwaladr  
University Health Board

## 5. Equipment Budget

We note the recommendations from the Welsh Neuromuscular Network for the provision of designated equipment budgets to enable minor purchases and care arrangements. We continue to work with partners across health and social care to support patient in promptly accessing the vital equipment needed.

Once again, I would like to thank you for seeking the views of the Health Board on the Petition.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'T. Purt', written over a horizontal line.

**Prof Trevor Purt**  
**Chief Executive**



26th May 2015

Mr William Powell AM  
Chair  
Petitions Committee  
National Assembly for Wales  
Cardiff Bay  
Cardiff  
CF99 1NA

Dear William,

P-04-532 – Improving specialised neuromuscular services in Wales.

Thank you for your letter of April 2015 regarding the above and seeking the views of Powys Teaching Health Board on the petition from the Muscular Dystrophy Campaign:-

*We call on the National Assembly of Wales to urge the Welsh Government to ensure that Health Boards implement the investment proposed by the Welsh Neuromuscular Network Vision Document for improving specialised neuromuscular services in Wales.*

In Powys teaching Health Board we have approximately four children/young people with muscular dystrophy and a further three with muscle wasting type conditions. Powys teaching Health Board has no District General Hospital and these people will have to travel some distance to specialist centres for specialist tests for diagnosis, specialist clinics, respiratory care, cardiac care, insertion of pegs for feeding and wheelchair appointments.

In Powys children and young people are supported locally as early as possible, often from babies, in order to fulfil their potential. Local services support families and carers once they have been given the diagnosis; local therapists will be assessing the physical health of the child or young person prior to clinic appointments, sharing assessments, arranging support of equipment for 24 hour postural management including sleep systems, seating, bathing, standing frames, advising and supporting on appropriate wheelchair provision, orthotic management with footwear, preventative chest care, provision of slings and advice on manual handling. Powys is able to deliver on equipment and support in a timely way. This is something we do well. (5)

Both Corfforedig (De)  
Neuadd Brycheiniog, Ffordd Cambrian,  
Aberhonddu, Powys LD3 7HR  
Ffôn: 01874 711661



Corporate Hub (South)  
Neuadd Brycheiniog, Cambrian Way,  
Brecon, Powys LD3 7HR  
Tel: 01874 711661

Rydym yn croesawu gohebiaeth Gymraeg  
Bwrdd Iechyd Addysgu Powys yw enw gweithred Bwrdd Iechyd Lleol  
Addysgu Powys



We welcome correspondence in Welsh  
Powys Teaching Health Board is the operational name of  
Powys Teaching Local Health Board

There is work going on through the Respiratory and Cardiac Delivery Plans that can be drawn on to improve these services for this service user group in Powys. Up-skilling local healthcare professionals and improving pathways for interventions such as genetic counselling, non invasive ventilation and cough assists devices have the potential to improve services for people with MND, SCI and MS as well as people with a neuromuscular conditions. We would support the development of the use of telemedicine to enable our local population access centralised specialist services more efficiently.

I hope this letter goes some way to clarifying the situation regarding the provision of neuromuscular services in Powys but should you have any further queries please do not hesitate to contact me,

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Carol Shillabeer', with a long, sweeping horizontal stroke at the end.

Carol Shillabeer  
Chief Executive



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CYMRU  
NHS  
WALES

Bwrdd Iechyd Prifysgol  
Abertawe Bro Morgannwg  
University Health Board

Our Ref: PR/cw

Date: 1<sup>st</sup> June 2015

ABMU Health Board  
Headquarters  
One Talbot Gateway, Seaway Parade,  
Port Talbot  
SA12 7BR

01639 683302  
WHTN: 1787 3302

Mr William Powell, AM  
Chair  
Petitions Committee  
National Assembly for Wales  
Cardiff Bay  
Cardiff  
CF99 1NA

Dear Mr Powell

### **P-04-532 - Improving Specialised Neuromuscular Services in Wales**

Thank you for your letter dated 23<sup>rd</sup> April 2015 requesting an update from ABMU Health Board on progress against the priorities identified.

#### **An Increase in Family Care Advisors**

Within South West Wales (ABMU and Hywel Dda Health Board) we have one Neuromuscular Care Advisor, Sarah Harris, who works 30 hours per week, 5 hours of which are funded by the previous Chair of the Neuromuscular Care Group in recognition of the need for increased availability of the advisor.

#### **Specialist Adult Neuromuscular Physiotherapists**

ABMU have redesigned existing specialist adult physiotherapy expertise to support the Adult Muscle Clinic, which was established in 2013, there has been no new specialist physiotherapy appointment in South West Wales. Advice for the more complex patients is an area which remains to be resolved.

#### **An Increase in Clinical Psychology**

There is currently no service provision for clinical psychology for patients with Muscular Dystrophy in South West Wales. There are meetings within the Health Board to look at the

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• Chairman/Cadeirydd: **Professor Andrew Davies**

• Chief Executive/ Prif Weithredydd: **Mr Paul Roberts**

ABMU Headquarters/ Pencadlys ABM, One Talbot Gateway, Seaway Parade, Baglan Energy Park, Port Talbot. SA12 7BR.  
Telephone: 01639 683344 Ffon 01639 683344 FAX: 01639 687675 and 01639 687676

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[www.abm.wales.nhs.uk](http://www.abm.wales.nhs.uk)

provision of Psychology services across a range of neurological conditions and this has been highlighted in the Neurological Conditions Delivery Plan as a priority area to address.

### **Additional Consultant**

Additional Neuromuscular consultant time to provide additional support would be beneficial.

### **Equipment**

2014/2015 also saw the allocation of significant non recurrent investment for the provision of equipment for patients with a neuromuscular condition. Deploying this resource during the year posed a challenge but was successfully delivered by the Neuromuscular Care Advisor for South West Wales, and has resulted in significant benefit for patients.

I would also like to provide some additional information regarding Adult Neuromuscular Care.

The Adult Muscle Clinic has now been running successfully for 2 years and is held every 6 weeks in the Specialist Rehabilitation Centre at Morriston Hospital. This is a Consultant Neurologist led clinic, co-ordinated and supported by the Neuromuscular Care Advisor with input from Specialist Physiotherapist, ECG and Lung Function services. The aim of the clinic is to provide a 'one stop' service for patients, with an MDT after each clinic to discuss each patient and decide individual action plans. The clinic was set up by innovatively using existing resources. Patients and families have welcomed this service.

A Transition Muscle Clinic has also been running successfully for 2 years and is held approximately 4 times a year. Patients transfer from Paediatric Neurology Muscle Clinic into this clinic. The Clinic is run jointly with a Consultant in Neuro Rehabilitation and the Transition Palliative Physiotherapist.

I hope you will see from the above that progress has been made, particularly around redesigning existing resources to improve care for patients with neuromuscular conditions.

We recognise however, that there is still much work to be done. The Integrated Medium Term Planning (IMTP) process is the mechanism the Health Board has for reviewing and prioritising its service development requirements and the outstanding issues outlined in this response will need to be considered alongside other priorities during 15/16.

If you require any further information or clarification please do not hesitate to contact me.

Yours sincerely



**PAUL ROBERTS**  
**CHIEF EXECUTIVE**

---

• Chairman/Cadeirydd: **Professor Andrew Davies**

• Chief Executive/ Prif Weithredydd: **Mr Paul Roberts**

ABM Headquarters/ Pencadlys ABM, One Talbot Gateway, Seaway Parade, Baglan Energy Park, Port Talbot. SA12 7BR.  
Telephone: 01639 683344 Ffon 01639 683344 FAX: 01639 687675 and 01639 687676

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Hywel Dda  
University Health Board

Ein cyf/Our ref: CEO.230b.0415  
Gofynnwch am/Please ask for: Nicola Gillies, PA to Chief Executive  
Rhif Ffôn /Telephone: 01267 239581  
Ffacs/Facsimile: 01267 239579  
E-bost/E-mail: [nicola.gillies@wales.nhs.uk](mailto:nicola.gillies@wales.nhs.uk)  
Dyddiad/Date: 06 July 2015

Swyddfeydd Corfforaethol, Adeilad Ystwyth  
Hafan Derwen, Parc Dewi Sant, Heol Ffynnon Job  
Caerfyrddin, Sir Gaerfyrddin, SA31 3BB

Corporate Offices, Ystwyth Building  
Hafan Derwen, St Davids Park, Job's Well Road,  
Carmarthen, Carmarthenshire, SA31 3BB

William Powell AM  
Chair  
Petitions Committee  
National Assembly for Wales  
Cardiff Bay  
Cardiff  
CF99 1NA

Dear Mr Powell

Thank you for your letter seeking Hywel Dda's view regarding the petition received by the Petition's Committee from the Muscular Dystrophy campaign. The petition calls for pressure to be brought on health boards to invest in implementing the recommendations of the Welsh Neuromuscular Network published in November 2013. This report called for investment in a number of national posts which are outlined within the petition and funding for specialist equipment.

Currently Hywel Dda accesses a specialist neuromuscular service hosted by ABMU with the Neuromuscular Family Care Advisor working in partnership with the local professionals providing hands on intervention and support. Of the 187 people who are projected to have a neuromuscular disorder in our patch, 75 adults and 16 children currently access this specialist service.

The WG Neurological Delivery Plan outlines a requirement to improve local services for people who have a neurological condition. In order to achieve this, a base line review has been undertaken which identifies a range of service gaps. One of those gaps is the availability of specialist community neuro rehabilitation. Local experience of a regional approach to condition specific rehabilitation services indicates that the local therapists continue to deliver the on-going hands on neuro rehabilitation.

Consequently it is our considered view that in order to serve our population and reduce gaps in provision we need to adopt a pragmatic approach to the

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Hafan Derwen, Parc Dewi Sant, Heol Ffynnon Job,  
Caerfyrddin, Sir Gaerfyrddin, SA31 3BB

Corporate Offices, Ystwyth Building,  
Hafan Derwen, St Davids Park, Job's Well Road,  
Carmarthen, Carmarthenshire, SA31 3BB

Cadeirydd / Chair  
**Mrs Bernardine Rees OBE**

Prif Weithredwr/Chief Executive  
**Mr Steve Moore**

Bwrdd Iechyd Prifysgol Hywel Dda yw'r enw gweithredol o'r Bwrdd Iechyd Lleol Prifysgol Hywel Dda  
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Mae Bwrdd Iechyd Prifysgol Hywel Dda yn amgylchedd di-fwg Hywel Dda University Health Board operates a smoke free environment

delivery of specialist community neuro rehabilitation, initially by establishing core specialist community neuro rehabilitation MDT working for a range of neurological conditions including muscular dystrophy.

Our intentions are outlined within our local Neurology Delivery Plan and include the establishment of a specialist neurological multidisciplinary team working locally across Hywel Dda. This team will include an Advanced Practice Physiotherapist and Advanced Practice Occupational Therapist, Speech & Language Therapist and Neuropsychologist supported by the current Neuromuscular Family Care Advisor for South Wales and additional Consultant neurology capacity.

This model fits more readily into a rural setting and is modelled on looking at the broader needs of people with neurological conditions and would make more sense and provide better value than developing further regional or national specialist posts which often don't provide the best access for more distant populations such as ours.

Our views are based on work that has been undertaken within our Population Health Programme, established to promote measurable system improvements in Health and Wellbeing for individuals, families and carers. One of the groups within the programme, as part of completing the baseline assessment of need for neurological conditions and has considered these needs in workshop settings together with service users, West Wales Neurological Alliance, a range of clinicians from Hywel Dda and ABMU and social care professionals in order to inform our model and action plan. The Neuromuscular Family Care Advisor for SW Wales has actively supported the Group in its work.

The Specialist MDT model described above has been proposed by the Population Health Group for early implementation utilising Welsh Government investment available to implement the Neurology delivery plan.

Yours sincerely



**Steve Moore**  
**Chief Executive**



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Bwrdd Iechyd Prifysgol  
Aneurin Bevan  
University Health Board

Our Ref: JP/RB/jr  
Your Ref: P-04-532

Direct Line: 01633 435905

17 June 2015

William Powell AC/AM  
Chair, Petitions Committee  
National Assembly for Wales  
Cardiff Bay  
Cardiff  
CF99 1NA

Dear Mr Powell

Re **Improving Specialised Neuromuscular Services in Wales P-04-532**

Thank you for your letter to the above received by the Health Board on 27 April. As you will be aware, my office contacted the Petitions Committee Office to ask for the deadline for this response and it was indicated that there was no fixed deadline. Therefore, I am pleased to provide the Health Board's response below to the petition being considered by the Committee from the Muscular Dystrophy Campaign.

**Petition Statement: We call on the National Assembly for Wales to urge the Welsh government to ensure that Health Boards implement the investment proposed by the Welsh Neuromuscular Network Vision document for improving specialised neuromuscular services in Wales.**

As you will be aware, Neuromuscular disorders comprise an array of conditions – many will be rare, but others are common such as Charcot Marie Tooth Disease.

Patients with complex needs and requiring highly expert multi-disciplinary input, and those entering a transition period between paediatric and adult services are best supported in Tertiary Clinics in Regional Neurosciences Centres such as the Peripheral Nerve Clinic in Cardiff run by one of our Consultants Dr Gareth Llewelyn.

For individuals with less complex needs, patients are seen at a more local level and this is a service provided by Consultant Neurologists in their General Neurology Clinics within Aneurin Bevan University Health Board.

Bwrdd Iechyd Prifysgol Aneurin Bevan  
Pencadlys, Ysbyty Sant Cadog  
Ffordd Y Llodj, Caerllion  
Casnewydd, De Cymru NP18 3XQ  
Ffôn: 01633 436700 (prif switsfwrdd)  
e-bost: abhb.enquiries@wales.nhs.uk

Aneurin Bevan University Health Board  
Headquarters, St Cadoc's Hospital  
Lodge Road, Caerleon  
Newport, South Wales NP18 3XQ  
Tel: 01633 436700 (main switchboard)  
e-mail: abhb.enquiries@wales.nhs.uk

[www.aneurinbevanhb.wales.nhs.uk](http://www.aneurinbevanhb.wales.nhs.uk)

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Bwrdd Iechyd Prifysgol Aneurin Bevan yw enw gweithredol Bwrdd Iechyd Lleol Prifysgol Aneurin Bevan  
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The new acute neurology service within the Health Board will see neuromuscular patients admitted to hospital within 24 hours. The aim however is to prevent unnecessary admissions and the roles of the Family Care Advisors, therapists, consultants and GPs are crucial in this regard.

The Health Board meets the Welsh Government Referral to Treatment times target for routine referrals. Urgent referrals are seen in 2-6 weeks

Currently there is no separate commissioning process for neuromuscular services in Wales. However, as part of the Neurological Conditions Implementation Group, £700,000 has been allocated to Neuro-rehabilitation across Wales and this includes Neuropsychology and specific funding has been approved to make the part time Family Care Advisor posts in South Wales full time appointments. Further work is being undertaken to clarify how this funding will be distributed but this additional funding will ease some of the burden on the workload of the Family Care Advisors to ensure that they can further support patients. This approach will be closely monitored. We will ensure that monitoring takes place of these services for patients with Neuromuscular Disorders as part of our neurological conditions Local Delivery Plan.

I hope this information is helpful to you. Should you require any additional information or clarification, please do not hesitate to contact me

Yours sincerely



**Judith Paget**  
**Chief Executive/Prif Weithredwr**

## **Muscular Dystrophy UK comment for the Petitions Committee on Welsh Neuromuscular Services**

Muscular Dystrophy UK acknowledges the correspondence from the Health Boards to the Petitions Committee.

However, Muscular Dystrophy UK retains concerns that focus on muscular dystrophy and related neuromuscular conditions, requiring input from a range of specialists including genetic, respiratory, rehabilitation and cardiac support, would be lost within a broader grouping of neurological conditions.

Muscular Dystrophy UK continues to repeat calls for neuromuscular service investment including:

- **increased neuromuscular care advisor support**
- **specialist adult neuromuscular physiotherapy**
- **long-term dedicated neuromuscular consultant time**
- **specialist neuromuscular psychology support**

While the Health Boards have recognised the need for improvements and highlighted the Neurological Conditions Delivery Plan, Muscular Dystrophy UK would encourage proactive engagement between Health Boards and the Welsh Neuromuscular Network to identify how Health Boards can meet the complex needs of neuromuscular patients.

For example, ABMU Health Board has recognised that additional neuromuscular consultant time would be beneficial. Muscular Dystrophy UK would like these comments to be pursued to establish how ABMU and other Health Boards across Wales can work collaboratively to meet this need which has been highlighted.

Muscular Dystrophy UK hopes that the urgent need for neuromuscular service development can be scheduled for a debate in the Assembly at the earliest available opportunity and can be considered by the Health and Social Care Committee.

## **P-04-640 Bring Down the Age of Smears to 18**

### **Petition wording:**

My 18 year old daughter has cervical cancer and we do not want this to happen to any other women just because of the age limit on smear tests. We would like to call on the National Assembly for Wales to urge the Welsh Government to bring the age down on the tests from 25 to 18.

### **Additional Information**

In March 2014 my daughter Jessica Bradford aged only 18 was diagnosed with cervical cancer. Because of her age she was not allowed a smear test. Jessica had all her cervical cancer injections in school. Jessica attends Velindre cancer hospital in Wales where her treatment was carried out – 5 chemotherapies, 30 radiotherapies and 3 internal radiotherapies. Due to this treatment Jessica can never carry her own children. Myself and Jessica have set up a page on Facebook to raise awareness, called Jess Bradford's cervical cancer awareness. Since doing the page we have met lots of mothers who have lost their daughters from cervical cancer

We are also currently collecting signatures on Change.org petitioning the UK Government on the same issue. Approximately 96,000 signatures have been collected so far..

**Petition raised by:** Julie Bradford

**Date petition first considered by Committee:**

**Number of signatures:** 525 signatures collected on the Assembly website. In excess of 1,000 signatures have been collected on a separate petition website about the same issue

**P-04-640 Bring Down the Age of Smears to 18 – Correspondence from the National Screening Committee to the Chair, 13.08.15**

**For the attention of William Powell**

Dear Mr Powell,

I enclose the UK National Screening Committee response to the petitions P-04-640 to bring down the age of cervical smear screening to 18.

Please note that we intend to send a hard copy of this response by post, including all the supporting documents. Could you please provide me with the most appropriate postal address in which to send by post to the petitions team.

Note, also that the letter has been scanned in and originally contained three electronic links to information available online, two of which are printable but are not available as electronic documents. Additionally, the paper summarising the review findings and listing all the consultation responses was too large to send electronically to your petitions e-mail account.

Therefore I have attached a link to these three documents below ahead of sending you hard copies.

These are for: –

- the [frequently asked questions](#) section of the cervical cancer screening page and
- the UK National Screening Committee [membership and terms of reference](#)
- the [review summary and consultation responses](#)

Please do get in touch regarding the appropriate postal address and if there is any additional information you require from the UK NSC.

Kind regards,

Hugh



UK National  
Screening Committee

Floor 2, Zone B  
Skipton House  
80 London Road  
London SE1 6LH  
T +44 (0)20 3682 0893  
[www.screening.nhs.uk](http://www.screening.nhs.uk)  
[@PHE\\_Screening](https://twitter.com/PHE_Screening)

Mr William Powell AC/AM  
Cadeirydd / Chair  
National Assembly for Wales  
Cardiff Bay  
CARDIFF  
Wales CF99 1NA

13 August 2015

Dear Mr Powell

Thank you for your enquiry regarding the 2012 UK NSC recommendation to increase the age of first invitation for cervical cancer screening.

I have provided some information below, and attached documents detailing the consultation process underpinning this recommendation.

The three month public consultation was opened to stakeholders and the general public on the 10<sup>th</sup> May and closed on the 10<sup>th</sup> August 2012. It is worth noting that many of the 30 consultation responses we received were from NHS or professional organisations in Wales, who were supportive of the recommendation to start cervical screening at 25. These included: the Welsh Medical Committee, the British Medical Association of Wales, the Royal College of General Practitioners Wales, Public Health Wales, Powys Teaching Health Board, the Welsh Pharmaceutical Committee, the Welsh Nursing and Midwifery Committee, Cardiff and Vale University Health Board and Velindre Trust.

Following the consultation, the review papers and subsequent consultation responses were discussed by the [UK National Screening Committee](#) on the 13<sup>th</sup> November 2012, who approved the recommendation to extend the first invitation for screening from 20 to 25 years old in Wales and Scotland.

It was noted upon reviewing the consultation responses that, while the professional organisations were clear about the reasons to raise the initial age of screening, there was a lack of understanding as to the purpose of cervical screening in some of the public responses received. So during the consultation period further clarification was provided using these [FAQs](#) to explain the aim of screening and the rationale for the change in screening.

These include: -

- The review finding evidence that screening women under the age of 25 causes more harm than good.


- That the correct management or treatment for suspected cancer is not a screening test.
- What would make the biggest difference to survival for young women with cervical cancer is for symptoms to be recognised and treated. *(To this end all GPs in Wales have been reminded of the appropriate action in suspected cervical cancer or abnormal bleeding)*. There is guidance for GPs to follow in identifying and sending selected cases directly to specialist care.
- Screening is not a test for cancer, but for abnormal cells which if left untreated can develop into cancer. However, these cells are very common in younger women and in the vast majority of cases will clear up of their own accord.
- If the results of a cervical screening test show abnormalities, the follow-up investigations may increase the risk of women subsequently suffering premature labour.
- It is now known that almost all cervical cancer is caused by HPV and since 2008 a vaccination programme has been underway for teenagers, which will greatly reduce their risk of cervical cancer when they are older.

Please see attached documentation including: the UK NSC minutes of the meeting where revised age for the first invitation to cervical screening was discussed, a paper summarising and listing all of the responses received as part of the consultation and the review papers that were originally considered by the UK NSC at this meeting. The latter papers include the discussion paper provided by the Welsh cervical screening programmes, the UK NSC review paper summarising the evidence and a PowerPoint Presentation using evidence to compare the impact that a programme with a first invitation to screen at 20 would have in comparison with one starting at 25.

I hope this information is of help and please do not hesitate to get in contact again should you require further information regarding this enquiry.

Yours sincerely



 David Walker  
Chair, UK National Screening Committee



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Iechyd Cyhoeddus  
Cymru  
Public Health  
Wales



Cervical Screening Wales  
Sgrinio Serfigol Cymru

# Discussion Paper on Age of First Invitation for Cervical Screening and Frequency of Invitation of Cervical Screening for Women aged 50 to 64 years

**Authors:** Dr Sharon Hillier, Miss Helen Beer, Dr Shantini Paranjothy, Dr Rosemary Fox, Mr Bryan Rose and Professor Hilary Fielder. Screening Division Public Health Wales NHS Trust

Based on papers prepared by Professor Hilary Fielder and Mr Huw Brunt

**Date:** May 2011

**Version:** 1

**Publication/ Distribution:**

- Public Health Wales (Intranet)
- Welsh Assembly Government

**Review Date:** Review in May 2012 or sooner if new information or evidence is available.

**Purpose and Summary of Document:**

The current policy for Wales is that women aged between 20 and 64 years are invited for cervical screening every three years. Scotland invite women aged between 20-60 years every three years. England and Northern Ireland invite women from 25 years of age and reduce the frequency of invitations to every 5 years for those aged between 50 and 64 years.

The purpose of this document is to review the evidence on which the age of

Cervical Screening Wales, Screening Division, Public Health Wales	Discussion paper on age of first invitation and frequency of invitation
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invitation and frequency of invitation is based and to discuss the implications of changes for the female population of Wales, for Cervical Screening Wales and for NHS Wales.

**Work Plan reference:** Cervical Screening Wales, Screening Division.

**DISCUSSION PAPER ON AGE OF FIRST INVITATION FOR CERVICAL SCREENING AND FREQUENCY OF INVITATION OF CERVICAL SCREENING FOR WOMEN AGED 50 TO 64 YEARS ..... 1**

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## 1 Executive Summary

This paper reviews the evidence base for the current cervical screening policy in Wales to ensure that waste, harm and variation are minimised.

Two distinct changes to the cervical screening programme are discussed:

- increasing the age of first invitation to screening from age 20 years to age 25 years
- increasing the screening interval for women aged 50-64 years from three years to five years.

These issues are considered independently.

The overall evidence base on which these changes are discussed is not strong as it derives from observational studies. However it is not realistic to expect that there will ever be randomised controlled trial evidence on which to base the decisions. Therefore the decisions need to be based on the balance of benefits and harms of the policy for the population.

Cervical Screening Wales considers that based on the current evidence the decision to increase the screening interval for women aged 50-64 years from every three years to every five years is highly acceptable.

Cervical Screening Wales considers that based on the current evidence regarding screening women aged 20-25 years, the balance of harms for the population outweighs the balance of benefit. As the population that has been offered Human Papillomavirus (HPV) vaccination reaches age of invitation to cervical screening, this balance of harms to benefit is more pronounced. The catch up population offered HPV vaccination at age 17/18 years in 2008 have been entering the programme from 2010 and the routine HPV vaccination at age 12/13 years will be entering the programme from 2014.

## 2 Context

The current cervical screening policy for Wales is that women aged 20-64 years are invited for screening every three years. The policy in Scotland is to invite women aged 20-60 years every three years. In 2003, England changed to invite women aged 25-64 and to standardise the frequency of invitation for those aged 50-64 to every five years. The decision for increasing the first age of invitation was based on a case control study published in 2003 which concluded that screening was less effective for young women.<sup>1</sup> Also there were concerns that as many young women had cellular changes that resolved spontaneously, screening could lead to unnecessary treatments, which could be a factor in premature delivery of subsequent pregnancies.<sup>2</sup> The decision for decreasing the frequency of screening from age 50 was based on results from the case control study published in 2003 which also concluded that five yearly screening offered similar protection to 3 yearly in this older age group.<sup>1</sup> In July 2010 Northern Ireland announced that they would change to the same policy as England from January 2011.<sup>3</sup>

The decision to change the age of invitation has been controversial and there has been a lot of public and press interest. This was heightened following the publicity around the death of the celebrity Jade Goody, who died from cervical cancer in 2009, aged 27. Following campaigns to lower the screening age from **Jo's Trust and others, the Department of Health** in England asked its National Advisory Committee on Cervical Screening to review the evidence. This was to ensure that the policy on starting screening at age 25 remained in the best interests of young women and was based on the latest available clinical evidence. The review took place at an extraordinary meeting of the Department of Health National Advisory Committee on Cervical Screening in May 2009 and concluded that the starting age of screening should remain at age 25.<sup>4</sup>

Scotland has convened an 'Age and Frequency of Cervical Screening subgroup' and the group has not made a decision to change the current policy and therefore women aged 20-60 years in Scotland are invited every three years.

The purpose of this paper is to review the evidence on which the age of invitation and frequency of invitation is based and to discuss the implications of changes for the female population of Wales and for the Cervical Screening Wales programme.

## **3 Background**

### **3.1 Screening**

Screening is a process of identifying apparently healthy people who may be at increased risk of a disease or condition. They can then be offered information, further tests and appropriate treatment to reduce their risk and/or any complications arising from the disease or condition.<sup>5</sup>

The UK National Screening Committee (UK NSC) advises Ministers and the NHS in the four UK countries about all aspects of screening. Using research evidence, pilot programmes and economic evaluation, it assesses the evidence for programmes against a set of internationally recognised criteria covering the condition, the test, the treatment options and the effectiveness and acceptability of the screening programme. Assessing programmes in this way is intended to ensure that they do more good than harm at a reasonable cost. The UK NSC also regularly reviews policy on screening for different conditions in the light of new research evidence becoming available.<sup>6</sup>

The Welsh Assembly Government takes advice from the UK NSC and makes the decision whether the screening programme is implemented for the population of Wales. The UK NSC recommends cervical screening to be undertaken but does not comment on the appropriate age range of frequency of invitation.

### **3.2 Cervical Cancer**

#### 3.2.1 Natural History

Cervical cancer is caused by Human Papillomavirus (HPV) which is a sexually transmitted infection. Persistent infection by high-risk HPV types is detectable in more than 99% of cervical cancers.<sup>7</sup>

The majority of high-risk HPV infections are transient and cause no clinical problems. Within one year, around 70% of new infections will clear and approximately 90% of new infections will clear within two years.<sup>8,9</sup> However, persistent infection by a high-risk HPV type is the most important causal factor for the development of cervical pre-cancerous and cancerous lesions.

Cervical intraepithelial neoplasia 1 (CIN 1) is a histologic diagnosis associated with benign viral replication and in most cases spontaneously regresses. Studies in adult women show regression rates of 70-80%

whereas in adolescents and young women show more than 90% regression.<sup>10</sup>

Cervical intraepithelial neoplasia 2 (CIN 2) is regarded as a precancerous lesion although many of these are known to regress. The annual regression rate of CIN 2 in adult women is estimated to range from 15%-23% with up to 55% regressing by 4-6 years.<sup>10</sup>

Cervical intraepithelial neoplasia 3 (CIN 3) is considered a true precancer with the potential to progress to invasive cancer at the rate of 0.2% to 4% within 12 months. (10) Progression times from CIN 3 to invasive carcinoma vary between 5 to 19 years.<sup>11,12,13</sup>

### 3.2.2 Risk Factors

The risk factors for cervical cancer are having sexual intercourse at a young age, having many sexual partners, not using condoms and smoking.

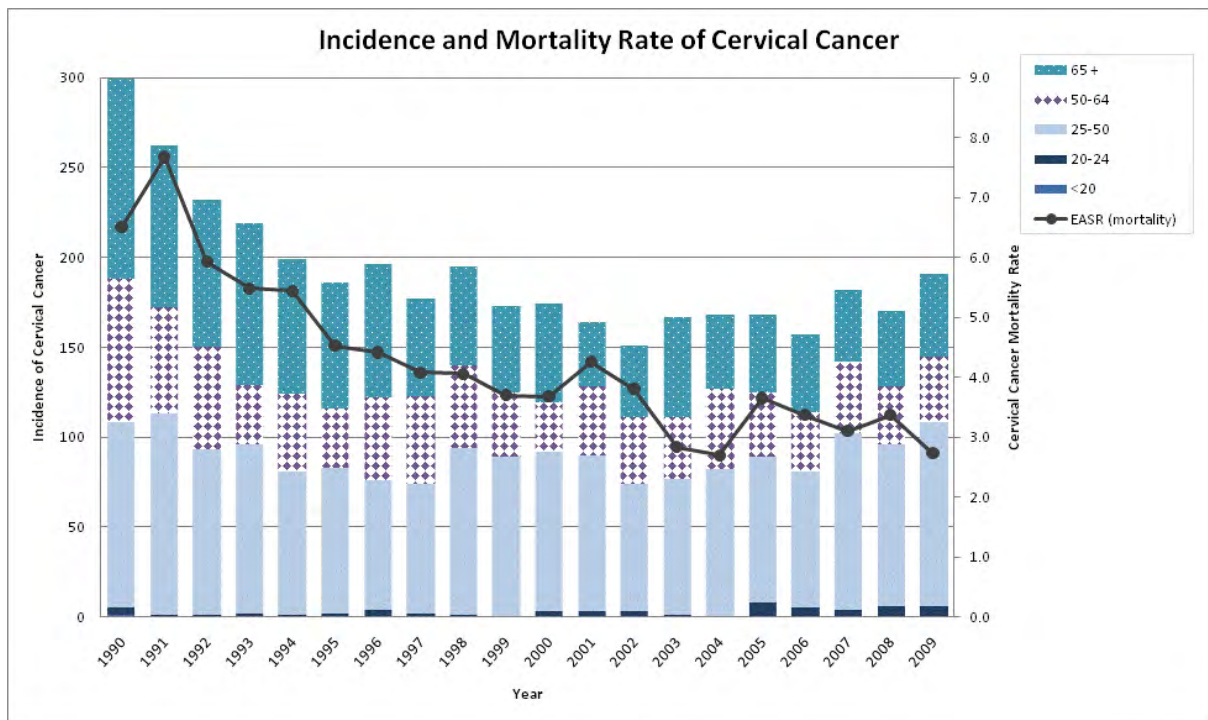
The 2006 Health Behaviour in School-aged Children Study showed that Wales had the fourth highest proportion of 15 year olds reporting having had sexual intercourse, (41% of girls and 30% of boys) out of 34 European and North American countries, and was higher than both Scotland and England.<sup>14</sup>

Young people (aged 16-24 years old) are the age group most at risk of being diagnosed with a sexually transmitted infection, accounting for 65% of all chlamydia, 50% of genital warts and 50% of gonorrhoea infections diagnosed in genitourinary medicine clinics across the UK in 2007.<sup>15</sup>

In 2008 it was estimated that 24% of people in Wales were smokers. Smoking is generally more common in younger people with more than twice as many 16 to 24-year olds being smokers (24%) compared to people aged 65 and over (10%).<sup>16</sup> Also, 12% of girls aged 13 in Wales reported that they smoked every week, which is twice the international average of 6%.

### 3.2.3 Epidemiology of Cervical Cancer in Wales

Figure 1



Sourced from WCISU data

Figure 1 shows the incidence of cervical cancer by age group from 1990 to 2009 and the European age standardised mortality rate. As can be seen the European age standardised mortality rate for cervical cancer has approximately halved since 1990.

With respect to the age of diagnosis of cervical cancer, the overall trend is that there were approximately half the number of diagnosis in the 65 year and older group and 50 to 64 years age group when comparing 1990 to 2009. However the 25 to 50 year old group does not show a sustained decrease and has similar incidence in 1990 compared to 2009. Although there are few diagnosis of cervical cancer for women aged between 20 and 24 years, over the time period shown, there has been a sustained increase in the incidence in this age group from 2005 to 2009.

The mean age specific rate per 100,000 for women aged 20-24 years for the time period 2005 – 2009 was 5.9.

### 3.2.4 Epidemiology of CIN2 and CIN3

The incidence of CIN3 has been increasing since the late 1980s in young women aged less than 35 years.<sup>17</sup> Prevalence of CIN 3 has increased in women aged 20-24 years which is consistent with more women in recent birth cohorts starting sexual activity in their mid teens. In England, there were over 3,000 women in 2002 that were registered with CIN3 in age group 20-24 years.<sup>18</sup>

The cohort of women resident in Wales aged 25 years at 1<sup>st</sup> Feb 2011, who had been ever been referred and treated in colposcopy (this was not limited to specific dates), either via screening or symptomatic services were reviewed to investigate the prevalence of CIN2 and CIN3 in this cohort. There were 20,225 women resident aged 25 years at 1<sup>st</sup> Feb 2011 and 1,725 had been referred to colposcopy previously, 1528 were referred as a result of an abnormal smear. Of those referred 302 (1.5%) had CIN2 diagnosed and 538 (2.7%) had CIN3 diagnosed. There were 16 diagnoses of cervical glandular intraepithelial neoplasia (CGIN) and 8 diagnoses of cervical cancer.

## 4 Cervical Screening Wales

### 4.1 Aim of Cervical Screening Wales

The aim of Cervical Screening Wales is to reduce the incidence of, and morbidity and mortality from, invasive cervical cancer.

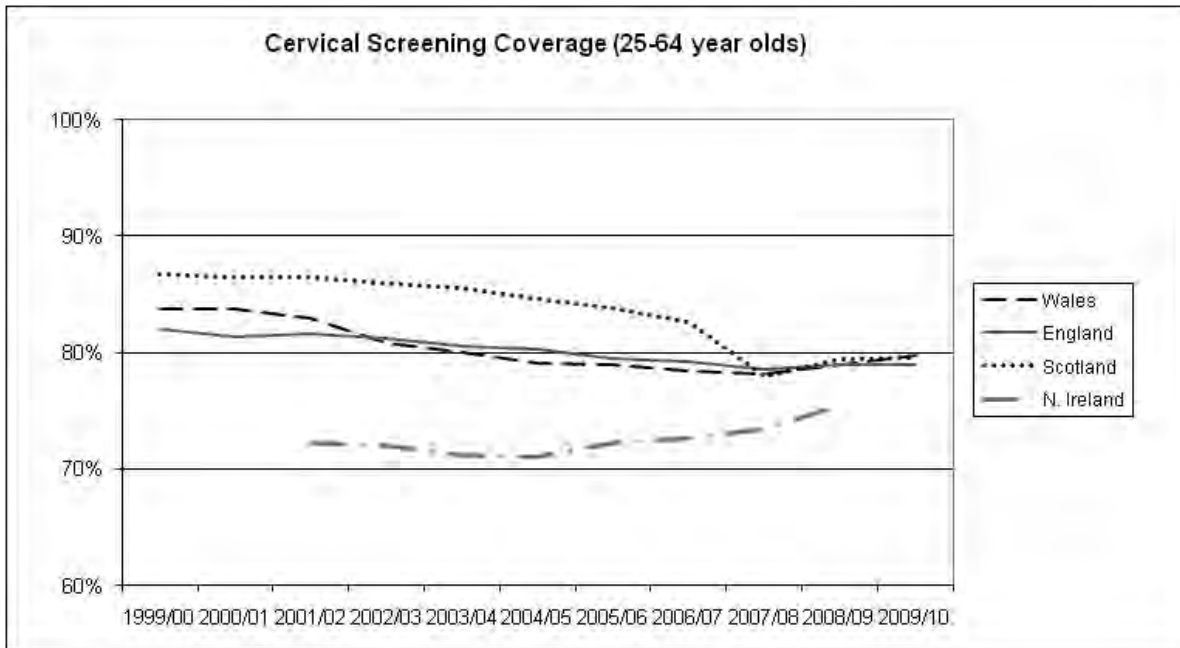
That is to undertake secondary prevention for cervical cancer by identifying cervical intraepithelial neoplasia lesions and treating these to prevent cancer from developing. On colposcopy some cancers are detected and although it is beneficial to treat these early (tertiary prevention) this is not the main reason for the cervical screening programme. Secondary and Tertiary prevention will be discussed separately.

### 4.2 Method

Women aged 20 to 64 years are sent an invitation letter to attend for a cervical screen every 3 years. Women can attend their General Practice or their local NHS Community & Sexual Health Clinic for a smear to be taken by a smear taker. The aim of the test is to detect early cell changes that may lead to cancer. The results are sent back to the women by post and if indicated the woman may be asked to attend for a repeat smear, or referred by Cervical Screening Wales to a colposcopy clinic for further investigation.

### 4.3 Coverage

Figure 2: 5 year Coverage for 25-64 years olds across UK for cervical screening (Data provided by screening information team, Screening Division)



The target standard in Wales is that 80% of eligible women aged 20 to 64 years have been adequately screened in the previous 5 years. Coverage is the proportion of people resident and eligible at a particular point in time who have been screened at least once in a defined time period.

The coverage rate of cervical screening in different countries of the UK is shown in Figure 2. This shows that for England, Wales and Scotland there has been a decline in the coverage rate over the last ten years. From 2000 to 2007 Scotland (invites up to age 60 years) has had the highest coverage of all of the countries and was consistently above the 80% target. England was above the target at the beginning of the period but dropped below 80% in around 2004/05 and then stabilised at about 79%. Wales was above the target until 2003/04 then dropped below 80% and remained below 80% until in 2007/08 when the coverage increased and nearly reached the 80% target in 2009/10. From 2001/02 to 2005/06 Northern Ireland had a stable coverage from 72% to 71% and was consistently lower than the other countries.

## **5 Age of First Invitation for Cervical Screening**

### **5.1 Current Policies in the UK**

The current policies in the UK for age of first invitation for cervical screening is 25 years of age for England and Northern Ireland and 20 years of age for Scotland and Wales.

### **5.2 Guidance**

The UK National Screening Committee has not specifically advised on age at first invitation to cervical screening.

The Advisory Committee on Cancer Prevention of the European Union concludes that screening should be concentrated in women aged 30-60 years and definitely not to include women younger than 20 years.<sup>19</sup>

The American Cancer society published guidelines in 2002 and recommended that cervical screening should either begin at the age of 21 years or 3 years after the initiation of sexual intercourse.<sup>20</sup>

**The World Health Organisation review stated 'There is minimal benefit and substantial harm in screening below the age of 25. Organized programmes should not include women aged less than 25 years in their target populations.'**<sup>21</sup>

### **5.3 Literature review**

Library and knowledge management service, Public Health Wales NHS Trust undertook a literature review in January 2011, to identify relevant articles that discussed the benefits and harms of screening 20-24 year old women (appendix 1). 80 articles were identified and on reviewing the abstracts 35 articles were selected in full. In February 2010 the NHS Cervical Screening Programme published a critical review of the literature on the impact of cervical screening on young women.<sup>22</sup> This was a focused review and stated that it was not a systematic literature review. The identified literature will be discussed under the defined questions which are relevant to the issues of inviting women aged 20-24 years for screening.

### 5.3.1 Does inviting women aged 20-24 years reduce the incidence of cervical cancer?

The intended benefit of inviting women at age 20 years is that their incidence of cervical cancer is reduced in the future by detecting and treating early cellular changes. However, it is difficult to estimate how many cervical cancer cases are prevented as not all precancerous changes will progress. In a study investigating the rate of progression of CIN2, 95 women with a mean age of 20.4 years; 2% (95%CI 1-9%) of patients showed progression to CIN3 by year 1; 12% (95% CI 8-22%) showed progression by year 2 and 15% (95% CI 9-26%) showed progression by year 3.<sup>10</sup>

#### **Evidence from observational studies**

The existing literature is limited because there are no randomised controlled trials able to be undertaken to investigate the effect of age on the effectiveness of cervical screening. The landmark meta analysis from the International Agency for Research on Cancer<sup>23</sup> provided no details regarding the age dependence of the results but stated that age did not affect either the sensitivity of cytological screening or the distribution of the sojourn time of the disease.

Case control studies have limitations as they depend on the underlying rate of cervical cancer in women who choose not to be screened, and this may be higher or lower than in the general population.<sup>24</sup> Much of the observational evidence on the protective effect of cervical screening at all ages is derived from case control studies.

The case control study published in 2003 by Sasieni et al<sup>1</sup> informed the decision made in England to invite women from age 25 years. A more recent analysis by the same authors<sup>25</sup> of 4,012 women aged 20-69 years with invasive cancer diagnosed in participating centres and two controls per case individually matched on age and area of residence. They found that there was no evidence that screening women aged 22-24 reduced the incidence of cervical cancer at ages 25-29 OR 1.11 (95% CI 0.83-1.50).

**Sasieni's** original study did not investigate the reduction in incidence of microinvasive cancers which are of particular importance in younger women, as fertility sparing options for treatment may be feasible.<sup>17</sup> However the more recent study did classify microinvasive cervical cancers as cases.

In 2006, a review of the evidence of benefit and harm of undertaking cervical screening in Wales for women aged 20-24 years was published.<sup>26</sup> A literature review was undertaken and Welsh data for the number of cases of CIN3 were examined and rates of invasive cervical cancer for young women calculated. The results were that following the introduction

of the Welsh organised call/recall cervical screening programme, cervical cancer had reduced from 4.2 to 2.2 mean age-specific rate per 100,000 women aged 20-24 years from 1981-88 to 1989-2003. The recommendations were to continue to invite women aged 20-24 years to cervical screening.

An Italian study in Florence<sup>27</sup> which compared the efficacy of screening women aged less than 40 and those aged 40 and older found that screening offered less protection to the younger women. A case control study in Australia found that screening every two years gave more protection for women aged over 30 years than those aged 20-29 years. However, the paper did conclude that there was benefit of screening women aged 20-29 years.<sup>28</sup>

A review of the Netherlands screening programme was published in 2008<sup>29</sup> to determine whether the target age for cervical cancer screening should be lowered below the age of 30. All cervical cancer cases diagnosed in The Netherlands between Jan 1989 and Dec 2003 were selected and trends described. The authors concluded that because of the incidence and mortality rates for cervical cancer among women younger than 30 were low and not increasing, then the screening age for invitation should remain at 30 years of age.

A Swedish audit<sup>30</sup> found no evidence of screening being less effective in young women and found a 60% reduction in cervical cancer incidence.

A recent paper reviewed the Icelandic experience<sup>31</sup> with respect to age-specific effectiveness, optimal targeted age range and intervals in cervical cancer screening using data from the screening programme with centralised records dating from 1964. The findings confirmed a significant increased rate in the screened population of CIN 2, CIN 3 and microinvasive cancer since 1979, mainly in the age group 20-34 years and that the lesions started to accumulate within 3 years of a normal smear. The study concluded that the lower age limit of 20 years should remain unchanged.

### **Evidence from modelling studies**

Canfell *et al*<sup>32</sup> predicted the impact of the 2003 changes in cervical screening practice in England on cervical cancer incidence rates using a markov stimulation model. Overall the predicted cumulative lifetime incidence of invasive cervical cancer in the UK was 1.7% in the absence of screening and 0.77% with the pre-2003 screening practice. A reduction in lifetime incidence to 0.63% was predicted following the implementation of the 2003 NHSCP recommendations. However, the benefit modelled was due to standardisation of the 3 year screening interval for women aged 25-49 years across England, which is standard practice in Wales anyway.

The model showed that screening women aged 20-25 years once in the 5-year period would have minimal impact with the cumulative lifetime incidence decreasing from 0.63% to 0.61%, even if coverage rates of over 75% were achieved in this age group.

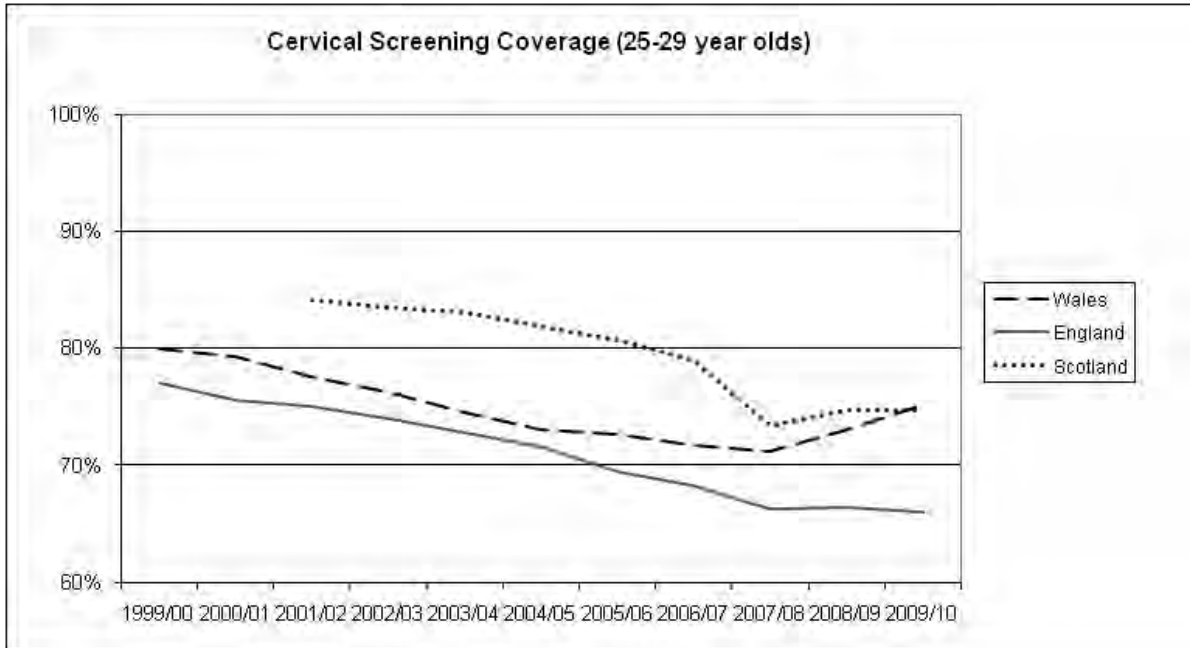
Peto *et al* <sup>24</sup> calculated the incidence and mortality for cervical cancer that would have occurred in England and Wales without the organised call and recall system implemented in 1988. Based on a cohort of women born in 1952, it was estimated that 1.5% of women would have died of cervical cancer before the age of 85, if they had never been screened, and 3% would have developed the disease.

Sasieni et al 2008 <sup>33</sup> estimated the cervical cancer rates that would have occurred in the absence of screening women aged 20-24 years using assumptions and past data on CIN registrations in England and Scotland from 1989 to 2004. The estimate was that at most 1.5% of women treated (equivalent to 3% of CIN3 registrations) would have had cancer by age 25. This data did not include welsh residents and did not model the numbers of cancers that would have been prevented in older age groups.

Estimation from Wales programme in 2006 <sup>26</sup> were that the Cervical Screening Wales potentially prevents one cancer and detects two micro-invasive cancers in the 20-24 year age group and prevents eight cancers in the 25-29 year age group each year. To achieve this 22,000 women in the age group 20-24 year old were tested each year and around 450 underwent large loop excision of the transformational zone (LLETZ). This estimate has been updated in section 4.4.3.

5.3.2 Does inviting women aged 20-24 year maintain and improve coverage in the future?

Figure 3 Cervical Screening Coverage for 25-29 years olds across UK countries. Data provided by screening information, Screening Division



Women aged 25-29 years have been shown to benefit from cervical screening<sup>25</sup> and it is important that the coverage rate for these women is sufficient. It is feasible that changing to inviting women from age 25 may affect the coverage of the cohort aged 25-29 years. Although it is not possible to evidence this effect, the trend of coverage across the UK shows variation between the different countries.

Figure 2 shows that overall Scotland has the higher coverage rate in the aged group 25-29 years although this has been reducing over time and in 2005/6 fell below the 80% target. England and Wales have been below the 80% target for the last 10 years and has been reducing over time with England having a consistently lower coverage than Wales. The difference between England and Wales was greater from 2005 and indeed from 2007 Wales has reversed the reduction with a marked improvement in coverage compared to England whose coverage has stabilised recently. In Wales there has been recently been a programme of work organised by the screening promotion team on increasing uptake in younger age groups and the downward trend has been reversed. Maintaining this coverage and working toward the target 80% is important to reduce the incidence of cervical cancer. It is possible that changing to inviting women to aged 25 years has reduced the coverage for this age group in England.

### 5.3.3 Does inviting women aged 20-24 years identify cervical cancers early (tertiary prevention)?

Although tertiary prevention of cervical cancer by identifying the cancers early is an advantage, this is not the main aim of the cervical screening programme.

A 12 year follow up study in the UK between 1985 and 1996 showed a reversal in the ratio of symptomatic to screen-detected cancers in women aged 25-34 years but no fall in the numbers of cancers.<sup>34</sup> This was interpreted as a clinical benefit as most screen detected cancers were diagnosed at an early stage with potential fertility conservation and good life expectancy prognosis.

**In Guys and St Thomas' NHS Foundation Trust from 1999 to 2006 24 of 32 cancers in women aged 20-34 years were screen detected and that percentage declined in subsequent 15 year age bands ( $p \leq 0.0001$ ).**<sup>35</sup>

In the paper by Sasieni<sup>1</sup> they looked in detail at 34 women with cervical cancer aged 20-24 years; 26 of these had a previously operationally negative smear. A review of the screening histories of the 13 women with stage 1B+ cervical cancer in this age group indicated that six of these cases were symptomatic.

### 5.3.4 Does inviting women aged 20-24 years affect birth outcomes for subsequent pregnancies?

For women in this age group there is concern about the possible impact on colposcopic interventions for future pregnancies. In a critical review of the literature published by the NHS Cervical Screening Programme<sup>22</sup> conflicting results from studies were reported. In 2007 a systematic review and meta analysis<sup>36</sup> of 27 studies found that LLETZ was significantly associated with preterm delivery with an overall Relative Risk of 1.70 (95% CI 1.24 -2.35). In the five further primary research studies conducted after the meta analysis four found that treatment was associated with an increased risk of preterm delivery and one found that the diagnosis of CIN3 was associated with preterm delivery and not treatment itself.<sup>22</sup> The majority of studies have been limited in their ability to take into account potential confounding factors that could be independently associated with being referred for colposcopy and preterm delivery for example maternal smoking, socioeconomic status and previous obstetric history.

A study to investigate this issue in Wales was undertaken by Screening Division and Cardiff University in collaboration with Swansea University<sup>37</sup>. The aim was to investigate whether treatment for precancerous changes to the cervix were associated with preterm birth in subsequent pregnancies in 174,100 women aged 20-39 years in Wales who received cervical screening between April 2001 and March 2004. The study found that compared to women who had negative cervical smears, the odds ratio for preterm birth (less than 37 weeks) was significantly increased in women who had colposcopy only (adjusted OR 1.54, 95% CI 1.32-1.80) and single excisional treatment (adjusted OR 1.77, 95% CI 1.47-2.13). Among women who were referred to colposcopy for abnormal cervical smears there was no increased risks of preterm birth or low birth weight for women who had treatment compared to women who had colposcopy and punch **biopsy only**. **The study's conclusion was that the increase risk of preterm births may be explained by other characteristics of women who had abnormal smears.**

#### 5.3.5 Does inviting women aged 20-24 year increase their anxiety?

It is reported in the literature that women who receive an abnormal smear result have increased anxiety, and their worries include fear that they have cancer, self blame, sexual guilt and concerns about infertility.<sup>38</sup> Most research has been on high grade abnormal smears however a study looking at 3500 women recruited to Tombola (trial of management of borderline and other low grade abnormal smear) found that women reported anxiety levels for low grade abnormal smear results which were consistent with those found in previous studies of women with high grade abnormal smear results. Stratification of the effect of age on anxiety was not discussed in any of the identified studies.

Also there were no studies identified that discussed the effect of different policies across the UK on age of invitation, as young women may have been anxious especially following media attention of the recent celebrity death from cervical cancer.

## 5.4 Description and outcome of Cervical Screening for 20-24 year olds in Wales

### 5.4.1 Secondary prevention of cervical screening

#### Coverage of Cervical Screening

As of 31<sup>st</sup> March 2010 there were 106,573 eligible women resident in Wales aged 20- 24.

The coverage rate of cervical screening in 20-24 year olds in Wales is lower than the overall rate for women aged 20-64 years. As of 31<sup>st</sup> March 2010, 54,123 (50.8%) of women aged 20 -24 years had a smear test within the last 3 years and 57,752 (54.2%) had a smear test within the last 5 years. Comparing this with the age group 25-29 years; 64,420 (65.3%) had a smear test within the last 3 years and 74,028 (75.1%) had a smear test with the last 5 years.

The overall rate for women aged 20-64 years for the same time period was 66.7% within the last 3 years and 76.5% within the last 5 years.

#### Results of the cervical screening

For the year April 09- March 2010, there were 31,139 adequate samples examined by the pathology laboratories from 20-24 year old women. Of these

25,472 (79.3%) were negative and would have routine recall in 3 years or annual smears

3,680 (11.5%) had borderline changes and repeat smear requested or referral

2,106 (6.6%) had mild dyskaryosis and repeat smear requested or referral

452 (1.4%) had moderate dyskaryosis and were referred to colposcopy

415 (1.3%) had severe dyskaryosis and were referred to colposcopy

14 (<0.1%) had query invasive carcinoma or glandular neoplasia and referred to colposcopy.

Therefore 21.7% of the women who had cervical screening had a further intervention following the results.

## **Outcomes of cohort of women, currently aged 25 years, referred to colposcopy**

The cohort of women aged 25 years and residents in Wales on the 1<sup>st</sup> of February 2011, who had ever been referred to colposcopy as a result of an abnormal smear, were followed up to review their outcomes. Databases were interrogated to obtain outcomes for women who attended colposcopy in Wales and those who attended colposcopy in England. Where a woman **had multiple referrals the information about the woman's treatment and diagnosis** was restricted to the same episode. Where a woman had two different abnormal referral smears these were counted as two episodes.

There were 1,774 referrals for 1,636 women and the worse outcome was CIN1 368 (20.7%), CIN2 298 (16.8%), CIN3 522 (29.4%), CGIN 16 (0.9%) and 7 (0.4%) cancers were diagnosed. 949 (53.5%) referrals resulted in treatment and 733 (41.3%) of these were for a LLETZ procedure.

The predictive positive value (PPV) can be calculated from the data to correlate high-grade cytology with histology. It records the proportion of cases in which a biopsy, following a screening test reported as moderate dyskaryosis or worse yield a histological diagnosis of CIN2 or worse. The PPV for the cohort of women age 25 years was 80.7% which was lower than the average PPV for Wales which was 83.3% for the time period 2005-2010.

The PPV for a histological diagnosis of CIN3 or worse for the cohort of women aged 25 years following a screening test, reported as moderate dyskaryosis or worse was 58.6%.

Overall the PPV for a histological diagnosis of CIN3 or worse for this population following an abnormal smear result, which prompted a referral for colposcopy, was 30.7%. This is low because the PPV for diagnosis of CIN3 or worse was low for those women identified with low grade dyskaryosis or borderline changes at 12.4%.

### 5.4.2 Tertiary prevention of cervical screening

Two separate look back exercises were undertaken for cervical cancer registrations in Wales in women aged less than 29 years, registered in 2007 and 2009. Age less than 29 years was chosen as one of the expected benefits for screening women aged 20-24 years is to reduce the risk of them developing cancer when older.

### **Cervical cancer registration in 2007 and aged less than 29 years**

In 2007 there were 182 cervical cancer registrations in Wales and 19 of these were less than 29 years of age (10.3%). At the time that the look back exercise was undertaken there were 17 on the cervical cancer register and it assumed that the remaining two were added at a later date.

An audit of these 17 registrations found that 12 of the 17 registrations were screen detected (70.6%) with 6 micro invasive cancers and 11 invasive cancers diagnosed. Only 4 of these were regular screeners and 8 were lapsed screeners. 3 of the 17 women were known to have died and none of these women were screen detected cancers, 2 of the women had never been screened and 1 was a lapsed screener.

Three of the registrations were women aged between 20 and 24 years. Two were regular screeners and the cancer was identified by screening and one was a lapsed screener whose cancer was not identified by screening. This young woman was known to have died.

### **Cervical cancer registration in 2009 and aged less than 29 years**

In 2009 there were 191 cervical cancer registrations in Wales and 24 of these were less than 29 years of age (12.5%).

An audit of these 24 registrations found that 19 were known to be screen detected (79%) with 9 micro invasive cancers, 6 invasive cancers, 2 adenocarcinomas, 1 not stated and one squamous cell cancer. Only 4 of these had been screened at the correct age intervals, remaining were lapsed screeners. Two of the 24 women registered with cervical cancer were known to have died and both these women had never been screened.

Six of the registrations were women aged between 20 and 24 years. Four women had their cancer diagnosed by screening and all were lapsed screeners. The remaining two women were diagnosed following symptomatic referral with one of the women never attending screening. This young woman was known to have died.

In summary these two look back exercises show that 71% and 79% of the cancers found in this age group were screen detected. Although this is not the primary aim of the screening programme the benefit of tertiary prevention does need to be considered for this population.

#### 5.4.3 Estimation of benefit and harm of Cervical Screening Wales

The outcome data shows that for the cohort of women who were aged 25 years as of 1<sup>st</sup> February 2011 and invited to screening from age 20 years, there were 1,774 referrals following an abnormal smear result and 949 referrals resulting in treatment. In this cohort there were 522 cases of CIN3 diagnosed. Using 0.2% as a minimum estimate and 4% as a maximum estimate of CIN 3 progressions to invasive cancer each year (10); the range of number of cancers prevented would be 1 to 21.

### **5.5 Implication of changes to age of invitation of screening for Cervical Screening Wales**

The implications of changing the first age of invitation for cervical screening from age 20 to age 25 are discussed with reference to the workload predictions.

The model is based on changing the call age from age 20 to age 25 at a defined point in time. Women aged between 20 and 25, who have already been invited to cervical screening, will continue to be invited as it would be unethical to stop once they were in the programme. This would mean that 21 year olds due to be sent reminder letters or early repeat smears would still be invited and women due for recall at age 23-24 will be sent their 3 year recall invitation. From the defined point in time there would be no new 20 year olds entering the programme.

The estimations of workload have been modelled for 6 years from the point of change for number of invitations, number of smear tests and colposcopy referrals. The average numbers from 2005 to 2010 have been used as the estimate on which to base the model and this does not take into account fluctuations in the population over time.

The set up of the model is that in year one the cohort aged 21-24 are invited as currently policy but no new 20 year olds are invited; in year two the cohort now aged 22-24 are invited as current policy but no new 20 or 21 year olds are invited; year three the cohort aged 23-24 remain invited but no new 20,21 or 22 year olds are invited; year four the cohort aged 24 remain invited but no new 20,21,22 or 23 year olds; in year five the cohort aged 25 and those aged 24 and 11 months are invited to the programme but no new 20,21, 22, 23 or 24 year olds; in year six the cohort aged from 24 years and 11 months have their first invitation to the programme.

It is assumed that the uptake rate and abnormal cytology detection rate remains unchanged in the age groups. This may not be the case and if more women have abnormal cytology at age 25 because they have not

been screened at ages 20-24 years, then this will need to be taken into account. There will be a small number of women that move into Wales that are currently called by CSW under 25 years that would be excluded in future, these have not been taken into account in the model. The effect of screening a population who has been offered HPV vaccination and the effect of using HPV testing is not within the remit of this model.

### 5.5.1 Modelling results

#### Number of Screening Invitations

Table 1 Invite women from age 25 years from implementation of change

	Average from 2005 to 2010	Year 1	Year 2	Year 3	Year 4	Year 5	Year 6
Total annual invitations all age groups	321406	306579	302519	293793	283673	277095	281690
Decrease per annum:		14826	18887	27613	37733	44311	39716 - 41616

Total decrease in cervical screening invitations over 5 years is estimated as 143,369

Years two, three and four are set as the minimum reduction predicted and are likely to be between the minimum and maximum reduction of 44311. This will be dependent on the time taken for women to respond to their invitation and the numbers being re-invited or re-tested based on their test result and this is difficult to predict.

Year 6 has the minimum reduction predicted as 39716 and maximum reduction of 41616 to take into account the potential increase in numbers of the cohort aged 25 years in six years time.

#### Number of Cervical Screening Tests

Table 2 Invite women from age 25 years from implementation of change

	Average from 2005 to 2010	Year 1	Year 2	Year 3	Year 4	Year 5	Year 6
Total annual tests all age groups	238288	229123	224064	219863	212839	207082	217582
Decrease per annum:		9165	14224	18425	25449	31206	20706 to 22206

Total decrease in cervical screening tests taken over 5 years is estimated as 98470

Years two, three and four are set as the minimum reduction predicted and are likely to be between the minimum and maximum reduction of 31206. This will be dependent on the time taken for women to respond to their invitation and the numbers being re-invited or re-tested based on their test result and this is difficult to predict.

Year 6 has the minimum reduction predicted as 20706 and maximum reduction of 22206 to take into account the potential increase in numbers of the cohort aged 25 years in six years time.

The model has assumed that the uptake rate remains unchanged when the policy is changed but this may not be the case.

### Number of Colposcopy Referrals

Table 3 Invite women from age 25 years from implementation of change

	Average from 2005 to 2010	Year 1	Year 2	Year 3	Year 4	Year 5	Year 6
Total annual colposcopies in all age groups	8858	8527	8094	7740	7308	6835	7570
Decrease per annum:		331	764	1118	1550	2024	1289-1394

Total decrease in colposcopy referrals over 5 years is estimated to be 5787.

In year six if we assume 7% of women in the 25-29 age group that are tested are referred to colposcopy (based on our current experience of this age group) we would expect between 630-735 extra colposcopies in this age group in year six. Year 6 has the minimum reduction predicted as 1289 and maximum reduction of 1394 to take into account the potential increase in numbers of the cohort aged 25 years in six years time.

Modelling the colposcopy referrals this has included both women referred with abnormal cytology and those referred symptomatically. It is not known whether stopping screening at age 20 years will cause an increase in the number of symptomatic referrals to colposcopy in this age group. It is assumed that the uptake rate and abnormal cytology detection rate remains unchanged in the age groups. This may not be the case and if more women have abnormal cytology at age 25 because they have not been screened at ages 20-24 years, then this will need to be taken into account.

## 5.6 Future issues

### 5.6.1 HPV vaccination status

In October 2007 Welsh Assembly Government announced that all 12 to 13 year old girls would be offered vaccination against two HPV virus types that cause 70% of cervical cancer.<sup>39</sup> The following year a catch up programme for 17-18 years olds was initiated and this was further accelerated in March 2009. As at November 2010, uptake across Wales of the HPV vaccine in girls in the 2009-10 School Year 8 was 85%, 83% and 77% for one, two and three doses respectively.<sup>40</sup>

In 2014 the cohort of girls who were offered vaccination aged 12 to 13 will be approaching 20 and therefore will be invited for cervical screening under the current policy in Wales. It is expected that this population will be at reduced risk of cervical cancer and therefore the benefits and harms of the screening programme will be different and it is probable that the benefits will be reduced. However, vaccination does not protect against all HPV virus types that cause cervical cancer and the uptake of the vaccine will not be 100%; therefore this population will still be at risk of cervical cancer. The evidence that will be required to inform this decision will be uptake of vaccination, efficacy of vaccination and surveillance to ensure that other high risk HPV virus types are not causing disease.

### 5.6.2 HPV Testing

In 2011 the NHS Cervical Screening Programme in England will begin incorporating HPV triage into their screening programme.<sup>41</sup> The sentinel site implementation project tested samples from women which contained cells with low-grade abnormalities (borderline or mild dyskaryosis). If they tested positive for high-risk HPV strains they were referred for colposcopy and if they were negative for high risk HPV strains they could be returned to routine recall. Wales has not been one of the pilot sites and is not currently undertaking HPV testing.<sup>41</sup>

**Other proposed uses for HPV test are 'test of cure' which will test for HPV following treatment and if negative the woman can have routine recall rather than yearly cytology follow up.**

The main application for the HPV test that would have an impact on age of invitation would be using HPV as the primary test rather than cytology. As the prevalence of HPV infection is likely to be higher in younger women, using HPV as the primary test may not be sufficiently specific for this population. The studies published on using the HPV test as the primary test have studied population aged 25 years and older. It would not be

feasible to use HPV as the primary test for this population without robust evidence that it is an effective test in this aged population. There will also need to be work around the feasibility of triage and test of cure in the population aged between 20-24 years.

## 5.7 Summary

There is not a strong evidence base on which to make recommendations on the starting age for cervical screening. The observational studies indicate that screening is not as effective in women aged 20-24 years, as the identified cellular changes can spontaneously regress. However, it is not possible to predict which lesions will regress and there will be a minority of women who will have an identified CIN3 or worse and will likely benefit from treatment. The prevalence of CIN3 for the cohort of women aged 25 years in Wales at Feb 2011 was found to be 2.7% (538 diagnosed out of 20,225 residents).

The other argument is that this population are child bearing age and there is evidence that undergoing LLETZ procedure increase the risk of preterm delivery of subsequent pregnancy. However, the studies were unable to adequately control for potential confounders to demonstrate the causality of this relationship. Indeed the study conducted in Wales<sup>37</sup> concluded that the increase risk of preterm births may be explained by other characteristics of women who had abnormal smears.

The predictive positive value for a histological diagnosis of CIN3 or worse for the cohort of women currently aged 25 years following any previous screening test reported as moderate dyskaryosis or worse was 58.8%. Overall the PPV for the population aged 25 years for predicting CIN2 or worse following a screening test reported as moderate dyskaryosis or worse was 80.7% which was lower than the overall PPV for the whole age range for the same time period at 83.3%.

Considering the issue of harms it is important to note that the PPV for a histological diagnosis of CIN3 or worse for the cohort of women aged 25 years following a screening test reported as low grade dyskaryosis or borderline changes was low at 12.4%.

Although tertiary prevention of identifying cancers early in this age group is not the aim of the screening programme, in two look back exercises 71% and 79% of the cancers found in this age group were screen detected. The incidence of cervical cancer in the age group 20-24 years has increased since 2005 and the mean age specific rate was 5.9 per 100,000 from 2005 to 2009.

Recently Wales has reversed the downward trend of young women attending for their smears and there needs to be careful management of

information on which age women should attend screening to minimise confusion.

The balance of benefit versus harm will be further changed from 2014 as the cohort of girls who were offered vaccination aged 12 to 13 will be approaching 20 and therefore will be invited for cervical screening under the current policy in Wales. It is expected that this population will be at reduced risk of cervical cancer and therefore the benefits and harms of the screening programme will be different and it is probable that the benefits will be reduced. However, vaccination does not protect against all HPV virus types that cause cervical cancer and the uptake of the vaccine will not be 100%; therefore this population will still be at risk of cervical cancer.

If HPV testing is used as a primary test or as triage in Wales, the population aged 20-24 will have to be considered independently as currently there is a dearth of information of the appropriateness of these tests in this age group.

Making the change to inviting women from age 25 years will affect the workload for cervical screening, smear takers, cytology and colposcopy services and this will need to be actively managed to ensure that services remain sustainable.

## **6 Frequency of Invitation of Cervical Screening for Women aged 50 years and older**

### **6.1 Current Policies in the UK**

The current policy for Wales for women aged 50-64 years is that they are invited for cervical screening every three years. The policy in Scotland is to invite women aged 50-60 years every three years. In 2003, England standardised their policy to invite women aged between 50-64 years every five years. In July 2010 Northern Ireland announced that they would change to the same policy as England from January 2011 (3).

The screening interval is different in different countries with USA having annual screening, Australia 2 yearly and Finland five yearly.

### **6.2 Guidance**

The UK National Screening Committee has not specifically advised on frequency of screening for women aged over 50 years.

### **6.3 Description and outcome of Cervical Screening for women aged 50 years and older**

The coverage rate of cervical screening in 50-64 year old in Wales:

Of the 243,448 eligible women resident in Wales at 31<sup>st</sup> March 2010 aged 50-64 years; 166,389 (68.3%) had a smear test within the last 3 years and 191,020 (78.5%) had a smear test within the last 5 years.

Of the 56,295 adequate samples from 50-64 year old eligible women, examined by the pathology laboratories from April 09- March 10, 54,399 (96.6%) were negative; 1,297 (2.3%) had borderline changes; 383 (0.7%) had mild dyskaryosis, 93 (0.2%) had moderate dyskaryosis; 78 (0.1%) had severe dyskaryosis; 11 (<0.01%) had query invasive carcinoma and 34 (0.1%) had query glandular neoplasia.

## 6.4 Effect of frequency of screening for women aged 50 years on benefits and harms of Cervical Screening

### 6.4.1 Literature review

In January 2011 the Library and Knowledge Management Service Public Health Wales, NHS Trust undertook a literature search to identify studies that describe the benefit and harms of changing cervical screening frequency from 3 to 5 years in women aged 50 year or older. The search identified 59 articles (Appendix 2), the abstracts of these were reviewed and 17 articles requested in full. The 17 articles were reviewed and other relevant articles identified and requested. The articles informed the discussion as detailed.

### 6.4.2 Will increasing the screening interval effect the incidence of cancer?

The evidence on which the screening interval was based was originally an international study conducted by the IARC that estimated yearly screening reduced the incidence of invasive cervical cancer by 94%, three yearly by 91%; five yearly by 84% and 10 yearly by 64%.<sup>42</sup>

In 2003 two studies were published which provided more evidence on screening frequency. The first paper (2) analysed screening histories of 1305 women aged 20-69 years, diagnosed with frankly invasive cervical cancer and 2532 age matched controls obtained from the UK screening programme database. Their analysis showed that by using time since the last operationally negative cytological smear 4.5 to 5.5 yearly screening offered 72% (95% CI 43%-86%) protection compared to 2.5-3.5 yearly screening protection of 85% (95% CI 74%-92%) for women aged 55-69 for frankly invasive cervical cancer.

The authors produced summary point estimates of protection and concluded that five yearly screening offered similar protection to 3 yearly. It is on the results of this paper that England standardised to inviting women aged 50-64 year every 5 yearly. This paper has age groups in 55-69 and the policy is 50 -64 to allow time from screening to cancer diagnosis. The issues are that the paper assumed that screening to cancer diagnosis does not vary by age from 50 to 55 years, the analysis did not include screen detected micro invasive cancers; there were 490 (18%) results that had cancer stage unknown which may have biased the results, and the data was from England and the population in Wales may be different.

A Dutch study published in 2004<sup>43</sup> supported a five year screening interval by reporting that the incidence of squamous cell carcinoma and precursor lesions remained stable when changing from a 3 year to 5 year screening interval. However this study did not stratify the results by age.

A paper published in 2004 which modelled the effect of implementation of the 5 year screening interval at age 50 years supported the recommendation of changes to cervical screening intervals.<sup>32</sup> However the actual outcomes have not yet been reported.

Unpublished work undertaken with Sasieni *et al* and Cervical Screening Wales explored the effectiveness of the screening programme in Wales between 1999 and 2007. The odd ratios for screening between 1990-2001 were compared to those between 1999-2007 and population attributable risks were calculated. A total of 1,466 cases of cervical cancer were diagnosed in Wales between 1999 and 2007, 73% of which were diagnosed in women aged 20-64 years. There was no evidence to suggest that extending the screening interval from 3 yearly to 5 yearly in women aged over 50 years increased the risk of developing cervical cancer (OR 0.17, 95% CI 0.11- 0.27 vs, OR 0.14 95% CI 0.08-0.24 respectively).

#### 6.4.3 Will increasing the screening interval affect coverage?

There was no information in the literature as to the effect of reducing the frequency of invitation to coverage of screening.

#### 6.4.4 Will increasing the screening interval have an effect on anxiety of the women?

There was no information in the literature as to the effect of reducing the frequency of invitation to anxiety

## 6.5 Implications of changes of frequency of screening for women aged 50 years and older to workload of Cervical Screening Wales

The implications of changing the frequency of intervention for women aged 50 years and older for the workload of Cervical Screening Wales are outlined. three different models are outlined:

- **Model 1:** no change – keep three-year routine recall;
- **Model 2:** change to five-year routine recall from date next smear test result is entered;

- **Model 3:** change current routine recall invitation dates from three to five-yearly recall (i.e. add two years to date of next invitation);

Data were obtained from the Exeter call-recall system and via laboratory pathology reports. Average numbers of smears taken and analysed as a **result of 'routine', 'early repeat' and 'other' recall types were calculated.** Averages were based on data collected during a complete round of screening from 2004 to 2006.

The modelling assumed that **numbers of 'early repeat' and 'other' recall test types were relative to the number of 'routine' recall tests taken in the previous year,** the screening population remained stable over time; only the routine recalls in women aged 50 years and over changes in each model, the rate of opportunistic cervical screening remained unchanged over time; that women are exactly 50 years old or more on the day that the smear is taken; and that the uptake by women for five-yearly screening was the same as for three-yearly screening.

This modelling only looks at the effect on the number of smears taken and does not take into account the effect on cytology results and colposcopy referrals. The modelling includes the total population invited for screening.

#### 6.5.1 Modelling results

**Table 4 Total number of screening tests undertaken implementing change in Year 2.**

MODEL	Year 1	Year2	Year3	Year 4	Year 5	Year 6	Year 7	Year 8	Year9	Year 10	Year 11	Year 12	Year 13	Year 14	Year 15	Year 16
1	221746	221746	221746	221746	221746	221746	221746	221746	221746	221746	221746	221746	221746	221746	221746	221746
2	221746	221746	221746	221746	179637	172061	211760	217122	218618	184550	176545	209013	214000	215960	188405	180382
3	221746	179637	172061	211760	217122	218618	184550	176545	209013	214000	215960	188405	180382	206896	211451	213655

**Table 5 Differences in number of screening tests comparing model to baseline (model 1 no policy change)**

MODEL	Year 1	Year2	Year3	Year 4	Year 5	Year 6	Year 7	Year 8	Year9	Year 10	Year 11	Year 12	Year 13	Year 14	Year 15	Year 16
1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
2	0	0	0	0	-42109	-49684	-9986	-4623	-3128	-37196	-45201	-12732	-7746	-5786	-33341	-41363
3	0	-42109	-49684	-9986	-4623	-3128	-37196	-45201	-12732	-7746	-5786	-33341	-41363	-14850	-10295	-8090

The main issue with increasing the frequency of the interval is that the stable number of test undertaken each year would change to have a sequence of peaks and troughs. To explain the reason for this using model 3, in year 2 the cohort of women aged 50-64 years would have their tests delayed two years (creating a trough in numbers) and be invited in year 5 in addition to those routinely invited in year 5 (creating a peak in numbers). Each year the cohort of women reaching age 50 will also have their invitation delayed and this further impacts on the peaks and troughs as modelled.

The greatest reduction in workload would be expected from the implementation of the policy change using model 3. Model 2 predicts that there is likely to be no change to the number of tests undertaken in the first three years following a change to the existing policy.

It would be important for any policy change that burden on the administrative service areas of the screening programme needs to be avoided and efforts to ensure that there are clear messages to screen takers and other programme professionals to minimise confusion.

## **6.6 Future issues**

### 6.6.1 HPV Testing

In 2011 the NHS Cervical Screening Programme in England will begin incorporating HPV triage into their screening programme.<sup>41</sup> The sentinel site implementation project tested samples from women which contained cells with low-grade abnormalities (borderline or mild dyskaryosis). If they tested positive for high-risk HPV strains they were referred for colposcopy and if they were negative for high risk HPV strains they could be returned to routine recall. Wales has not been one of the pilot sites and is not currently undertaking HPV testing.<sup>41</sup>

Other proposed **uses for HPV test are 'test of cure' which will test for HPV** following treatment and if negative the woman can have routine recall rather than yearly follow up.

The implementation of HPV as a primary test in the population aged 50-64 years needs to be modelled and it is possible that changing the testing method may improve the efficiency of cervical screening in this age group.

## 6.7 Summary

There is not a strong evidence base from randomised controlled trials on which to base the decision on screening interval for women aged between 50 and 64 years. The observational studies undertaken indicate that increasing the interval between screening invitations for this age group does not increase their risk of developing cervical cancer.

There was variation of screening intervals in England before 2003 and one of the benefits of introducing this policy was standardisation across England, there is standardisation already in Wales.

The uptake of women in this age group of cervical screening is good as 5 year coverage was 78% of eligible women resident in Wales at 31<sup>st</sup> March 2010. The prevalence of a test result indicating moderate or severe dyskaryosis was low in this age group at 0.2% and 0.1% respectively.

The argument made against screening women aged 20-24 years does not hold true for this population as they are not child bearing age and spontaneous regression of cellular changes are not an issue. Therefore, the issue is the efficiency of 3 yearly screening compared to 5 yearly screening.

## 7 Discussion

Two distinct changes to the cervical screening programme are discussed in this paper and the interconnection between these changes needs to be taken into account. Both changes if implemented will result in a decrease in invitations to screening, number of screening tests and resultant colposcopy referrals. These will need to be modelled in tandem to understand effects to the service if there are changes proposed.

The evidence base on which these changes are discussed are not strong as they are observational studies. However it is not realistic to expect that there will be randomised controlled trial evidence on which to base the decision. The overall benefits and harms for cervical screening needs to be considered for these two distinct populations.

This paper has not discussed the benefits and harms of screening women aged between 20 and 24 years who have been vaccinated against HPV and has not taken into account any other screening test methodology such as HPV as a primary test. The balance of harms and benefits will be different for a vaccinated population and these will need to be outlined. However, this will depend on how good the uptake of the complete vaccination course has been in this population. There will be issues around using HPV test on this population as there is currently no published data

on testing younger women in this way. Although the HPV vaccination will not be a factor in the decision to decrease the frequency of cervical screening for women aged between 50 and 64 years, the implications of HPV testing both as primary test, triage and test of cure will need to be explored.

## 8 Recommendations

1. Cervical Screening Wales (CSW), Screening Division makes the following recommendations to the Welsh Screening Committee for consideration: Screening policy in Wales should be altered to increase the screening interval for women aged 50-64 years from every three years to every five years. This change should take place as soon as possible.
2. Screening policy in Wales should be altered to increase the age at first invitation from 20 to 25 years. Women who are aged less than 25 years and have already been invited to the screening programme should continue to be screened according to the current policy.

Implementation and timing of these changes should be managed in such a way as to

- ensure that the reduction in numbers can be managed by the service effectively
- ensure clear communication and training to professional groups who undertake the cervical screening
- ensure clear communication to the public especially to women who would be expecting to be called for screening and those who have been offered HPV vaccination

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Cervical Screening Wales, Screening Division, Public Health Wales	Discussion paper on age of first invitation and frequency of invitation
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## Appendix 1

<b>Topic: Cervical screening</b>
<p><b>Search question:</b></p> <p><b><i>1 To identify studies that describe the benefits and harms of cervical screening in women aged 20 -25 years. Including; cervical cancer incidence, cervical cancer mortality or morbidity, anxiety, cost effectiveness, birth outcomes for future pregnancies and coverage.</i></b></p>
<b>For : Dr Sharon Hillier, Screening Division</b>
<b>By: Sian King, LKMS Swansea</b>
<b>Date : 26/01/11</b>
<b>Updated:</b>

<b>1.Methodology</b>	
<b>Search terms</b> : -Keywords, Free text	<p>Cervical screening</p> <p>Age adj4 25</p> <p>Young adj women</p>
<b>Database subject headings:-</b> MESH, HMIC	<p>Ablation techniques/ae</p> <p>Cancer screening</p> <p>Carcinoma squamous cell/di, pc</p> <p>Cervical cancer</p> <p>Cervical cancer-prevention and screening</p> <p>Cervical intraepithelial neoplasia</p> <p>Cervical screening</p> <p>Cervix neoplasms,</p> <p>Cervix uteri/ab</p> <p>Cervical cytology</p>

	<p>Colposcopy</p> <p>Electrosurgery/ae</p> <p>Mass screening</p> <p>Papillomavirus infections</p> <p>Screening</p> <p>Screening programmes</p> <p>Screening services</p> <p>Squamous cell carcinoma</p> <p>Uterine cervical neoplasms</p> <p>Uterine cervix</p> <p>Uterine cervix cancer</p> <p>Uterine cervix carcinoma</p> <p>Uterine cervix carcinoma in situ</p> <p>Uterine cervix tumor</p> <p>Uterus cancer</p> <p>Vagina smear</p> <p>Vaginal smears</p> <p>Adolescent</p> <p>Age distribution</p> <p>Age factors</p> <p>Age of onset</p> <p>Early diagnosis</p> <p>Early detection of cancer</p> <p>Women</p> <p>Young people</p> <p>Young adults</p> <p>Anxiety</p>
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	<p>Distress</p> <p>Costs</p> <p>Cost effectiveness</p> <p>High risk pregnancy</p> <p>Pregnancy complications</p> <p>Pregnancy high risk</p> <p>Pregnancy outcome</p> <p>Premature birth</p> <p>Risk factors</p> <p>Data</p> <p>Incidence of disease</p> <p>Incidence</p> <p>Statistical data</p> <p>Tabular data</p>
<b>Limits</b>	
<ul style="list-style-type: none"> <li>• Publication types</li> </ul>	Guidelines, reviews, reports, articles
<ul style="list-style-type: none"> <li>▪ Language</li> </ul>	English
<ul style="list-style-type: none"> <li>▪ Dates covered</li> </ul>	2000-2011
<ul style="list-style-type: none"> <li>▪ Geographical location</li> </ul>	Worldwide (developed countries)
<b>Other criteria</b>	
<b>Filters</b>	

<b>2. Sources</b>	
<b>(i) Core databases/sources</b>	
<a href="#">BNI</a>	27/01/11
<a href="#">CINAHL</a>	27/01/11
<a href="#">Clinical Evidence</a>	n/a
<a href="#">Cochrane Library</a>	27/01/11
<a href="#">EMBASE</a>	27/01/11
<a href="#">HMIC</a>	26/01/11
<a href="#">MEDLINE</a>	26/01/11
<a href="#">NICE</a>	27/01/11
<a href="#">Library catalogue &amp; knowledge base</a>	26/01/11
<a href="#">PsycINFO</a>	27/01/11
<a href="#">Public Health Wales Document database</a>	

<b>(ii) Topic specific databases, sources</b>	
<b>Databases</b>	
<b>Websites</b>	
ACOG	27/01/11
Department of Health	26/01/11
<a href="#">National Breast and Cervical Cancer Early Detection Program</a>	27/01/11

Cervical Screening Wales, Screening Division, Public Health Wales	Discussion paper on age of first invitation and frequency of invitation
---	---

<a href="#">NI Cancer Screening Programme</a>	27/01/11
<a href="#">NHS Cervical Screening Programme</a>	26/01/11
NHS Evidence – specialist collection	28/01/11
NHS National Services Division (Scotland)	27/01/11
RCOG	27/01/11

<b>(iii) Meta search engines</b>	
<a href="#">Google/Google Scholar</a>	
<a href="#">Intute</a>	
<a href="#">SUMsearch</a>	
<a href="#">TRIP</a>	

## Appendix 2

<b>Topic: Cervical screening</b>
<b>Search question:</b>  <i>To identify studies that describe the benefits and harms of changing cervical screening frequency from 3 year to 5 years in women aged 50 years or older. These could included cervical cancer incidence, cervical cancer mortality or morbidity, anxiety, cost effectiveness and coverage.</i>
<b>For : Dr Sharon Hillier, Screening Division</b>
<b>By: Sian King, LKMS Swansea</b>
<b>Date : 31/01/11</b>
<b>Updated:</b>

<b>1.Methodology</b>	
<b>Search terms</b> :-Keywords, Free text	Cervical screening Age\$ adj4 50 Over 50\$ Interval\$
<b>Database subject headings:-</b> MESH, HMIC	Cancer invasion/di, pc Cancer screening Carcinoma squamous cell/di, pc Cervical cancer Cervical cancer-prevention and screening Cervical intraepithelial neoplasia Cervical screening Cervix neoplasms, Cervix uteri/ab Cervical cytology

	<p>Mass screening</p> <p>Papillomavirus infections</p> <p>Screening</p> <p>Screening programmes</p> <p>Screening services</p> <p>Squamous cell carcinoma</p> <p>Uterine cervical neoplasms</p> <p>Uterine cervix</p> <p>Uterine cervix cancer</p> <p>Uterine cervix carcinoma</p> <p>Uterine cervix carcinoma in situ</p> <p>Uterine cervix tumor</p> <p>Uterus cancer</p> <p>Vagina smear</p> <p>Vaginal smears</p> <p>Age distribution</p> <p>Age factors</p> <p>Age of onset</p> <p>Early diagnosis</p> <p>Early detection of cancer</p> <p>Elderly : Screening</p> <p>Women</p> <p>Age</p> <p>Aged</p> <p>Middle age</p> <p>Middle aged</p> <p>Middle aged (45+ years)</p> <p>Older people</p>
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	<p>Over 50s</p> <p>Anxiety</p> <p>Distress</p> <p>Costs</p> <p>Costs and cost analysis</p> <p>Cost benefit analysis</p> <p>Cost savings</p> <p>Cost effectiveness</p> <p>Cancer risk</p> <p>High risk population</p> <p>Risk factor</p> <p>Risk factors</p> <p>Target setting</p> <p>Time</p> <p>Time factors</p> <p>Data</p> <p>Incidence of disease</p> <p>Incidence</p> <p>Statistical data</p> <p>Tabular data</p>
<b>Limits</b>	
<ul style="list-style-type: none"> <li>• Publication types</li> </ul>	Guidelines, reviews, reports, articles
<ul style="list-style-type: none"> <li>▪ Language</li> </ul>	English
<ul style="list-style-type: none"> <li>▪ Dates covered</li> </ul>	2000-2011
<ul style="list-style-type: none"> <li>▪ Geographical location</li> </ul>	Worldwide (developed countries)
<b>Other criteria</b>	

Cervical Screening Wales, Screening Division, Public Health Wales	Discussion paper on age of first invitation and frequency of invitation
---	---

<b>Filters</b>	

<b>2. Sources</b>	
<b>(i) Core databases/sources</b>	
<a href="#">BNI</a>	01/02/11
<a href="#">CINAHL</a>	02/02/11
<a href="#">Clinical Evidence</a>	n/a
<a href="#">Cochrane Library</a>	31/01/11
<a href="#">EMBASE</a>	01/02/11
<a href="#">HMIC</a>	31/01/11
<a href="#">MEDLINE</a>	31/01/11
<a href="#">NICE</a>	01/02/11
<a href="#">Library catalogue &amp; knowledge base</a>	31/01/11
<a href="#">PsycINFO</a>	01/02/11
<a href="#">Public Health Wales Document database</a>	

<b>(ii) Topic specific databases, sources</b>	
<b>Databases</b>	

Cervical Screening Wales, Screening Division, Public Health Wales	Discussion paper on age of first invitation and frequency of invitation
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<b>Websites</b>	
ACOG	01/02/11
AHRQ (US)	31/01/11
Department of Health	01/02/11
<a href="#">National Breast and Cervical Cancer Early Detection Program</a>	01/02/11
<a href="#">NI Cancer Screening Programme</a>	01/02/11
<a href="#">NHS Cervical Screening Programme</a>	01/02/11
NHS Evidence – specialist collection	02/02/11
NHS National Services Division (Scotland)	02/02/11
RCOG	02/02/11

<b>(iii) Meta search engines</b>	
<a href="#">Google/Google Scholar</a>	
<a href="#">Intute</a>	
<a href="#">SUMsearch</a>	
<a href="#">TRIP</a>	

# Clinical Practice Guidance for the Assessment of Young Women aged 20-24 with Abnormal Vaginal Bleeding



## Background

A recent review by the Advisory Committee for Cervical Screening recommended no change to the age of commencing cervical screening and that the screening range would remain at 25-64 years.

This decision was based on the potential for more harm, through morbidity consequent to screening, than benefit achieved by preventing cervical cancer. It was recognised, however, that in the rare cases of cervical cancer which do occur in women younger than 25 years (around 50 per year, with 0-5 deaths). There is a delay in diagnosis in a significant proportion because of delayed pelvic examination following self-referral with abnormal bleeding. The explanation for these delays, which have been documented at 4-6 months in some cases, is that relatively common symptoms of abnormal vaginal bleeding may be attributed initially to dysfunctional bleeding, or related to oral contraceptive use. The ACCS recommended the development of clinical practice guidance, which would reduce the risk of a delayed diagnosis of cervical cancer, by identifying those women most at risk of cervical cancer.

## The Size of the Problem

The number of women aged 20-24 years who develop cervical cancer is generally fewer than 50 cases per year and this will fall over the next 10 years as a consequence of the national HPV vaccination programme. By contrast abnormal vaginal bleeding is relatively common in this age group. It has been estimated from a general practice dataset in Scotland (unpublished) that postcoital bleeding is reported by around 1 in 600 women aged 20-24 per year. Intermenstrual bleeding is more common than this and it may be that 0.5-1% of women in this age present with abnormal vaginal bleeding each year. There are around 1.5m women aged 20-24 in England and it could, therefore, be estimated that 7,500 – 15,000 women per year will report abnormal vaginal bleeding. In practice the number could be larger than this.

## Developing a Guidance for Clinical Practice

The cardinal symptom of cervical cancer in this age group is postcoital bleeding, but persistent intermenstrual bleeding, which is more common, also requires attention. The critical intervention in the diagnosis of cervical cancer is an immediate speculum examination as recommended by SIGN2 and NICE3 Guidance, to enable a clear view of the cervix. Following a relevant history, it is, therefore, necessary for women who present with postcoital bleeding or persistent intermenstrual bleeding to be offered a speculum examination either in primary care or at a GUM clinic. This could be performed by a practice nurse experienced in cervical screening.

If the cervix looks abnormal and suspicious, which will be the case in a very small proportion, the correct action is urgent referral to colposcopy under the 'two week wait' rule. If there is a benign lesion, such as cervical polyp, a routine gynaecological referral will suffice. If the cervix looks normal, the recommended action will be a pregnancy test and testing for cervical infection (e.g. Chlamydia, N Gonorrhoea, Herpes), which could be performed in general practice, family planning clinics or GUM clinics. Any positive tests for sexually transmitted infections would need to be appropriately treated.

This pathway is illustrated below.

The impact of this guidance will be monitored by the Advisory Committee for Cervical Screening.

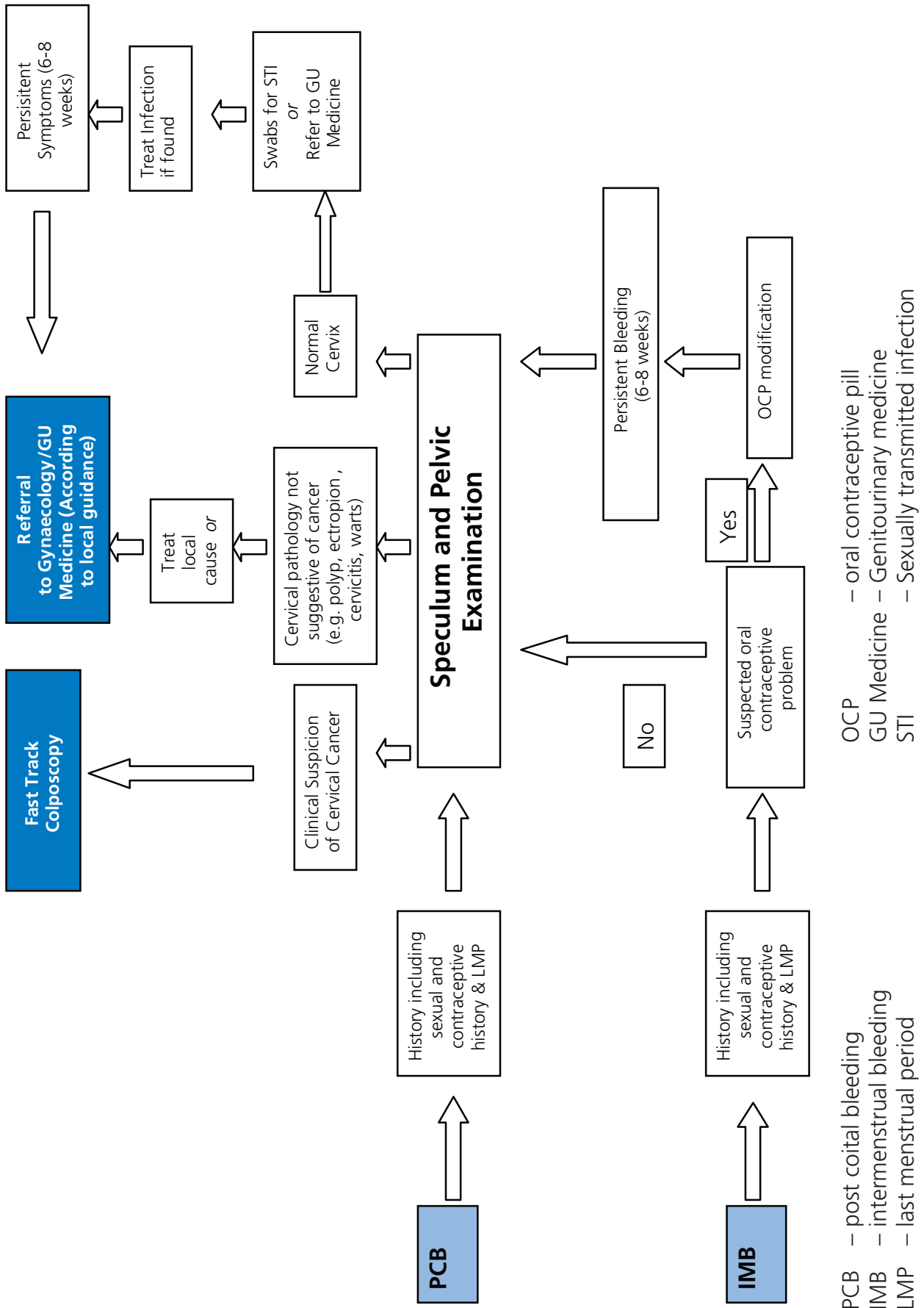
NHS Cancer Screening Programmes produce *Cervix chart for sample takers in primary care*, with pictures of the cervix showing various abnormalities. Copies of the chart can be ordered from [www.orderline.dh.gov.uk](http://www.orderline.dh.gov.uk), quoting NHSCSP publication No 25.

## References

1. Cancer Research UK Cancer Stats, Cervical cancer mortality by age  
<http://info.cancerresearchuk.org/cancerstats/types/cervix/mortality/index.htm>  
Accessed 25th January 2010.
2. Scottish Intercollegiate Guidelines Network (SIGN). Guideline 99, page 4, Management of Cervical Cancer, January 2008, Edinburgh, <http://www.sign.ac.uk/pdf/sign99.pdf>  
Accessed 25th January 2010.
3. National Institute for Clinical Excellence (NICE)/The National Collaborating Centre for Primary Care (NCC-PC) Referral guidelines for suspected Cancer in adults and children, page 68. June 2005. <http://www.nice.org.uk/nicemedia/pdf/CG027fullguideline.pdf>  
Accessed 25th January 2010.

This guidance was developed by a working Subgroup of the Advisory Committee on Cervical Screening:

HC Kitchener	(ACCS Chair)
C Sonnex	(ACCS, GUM)
J Butler	(DH, Gynaecology)
S Firth	(ACCS, GP)
K Moss	(ACCS, GP)
M Shafi	(ACCS, Gynaecology)
P Walker	(Invited member, Gynaecology)



# **Age of first invitation for Cervical Screening and frequency of invitation for women aged between 50-64years UK NSC policy review**

## **DRAFT 4**

### **Background**

UK policy on age of commencement and frequency for cervical screening is varied. England and Northern Ireland start at age 25 while Wales and Scotland at age 20. The UK National Screening Committee (UK NSC) has been asked by the Wales Screening Committee to produce a definitive UK NSC policy.

This document is a summary of reviews produced for all four UK countries and I am grateful to the authors for allowing us to quote directly from their reports.

### **Introduction**

The aim of cervical screening is to reduce the incidence, and morbidity and mortality from invasive cervical cancer.

The current cervical screening policy for Wales is that women aged 20-64 years are invited for screening every three years. The policy in Scotland is to invite women aged 20-60 years every three years. In 2003, England changed policy to invite women every three years for those aged 25-49 and every five years for those aged 50-64. The decision for increasing the first age of invitation was based on a case control study published in 2003, which concluded that screening was less effective for young women.<sup>1</sup> Also there were concerns that because many young women had cellular changes that resolved spontaneously, screening could lead to unnecessary treatments, which could be a factor in premature delivery of subsequent pregnancies.<sup>2</sup>

The English cancer screening programmes decision to amend national policy for screening women aged 50-64 was based on results from the case control study published in 2003 which concluded that five yearly screening offered similar protection to three yearly in this older age group.<sup>1</sup> In July 2010 Northern Ireland announced that they would change to the same policy as England from January 2011.<sup>3</sup>

The decision to change the age of invitation has been controversial and there has been a lot of public and press interest. This was heightened following the publicity around the death of Jade Goody, a celebrity who died from cervical cancer in 2009, aged 27. Following campaigns to lower the screening age from Jo's Trust and others, the Department of Health in England asked its Advisory Committee on Cervical Screening (ACCS) to review the evidence. This was to ensure that the policy on starting screening at age 25 remained in the best interests of young women and was based on the latest available clinical evidence. The review took place at an extraordinary meeting of the Department of Health Advisory Committee on Cervical Screening in May 2009 and concluded that the starting age of screening should remain at age 25.<sup>4</sup>

## **Cervical Cancer**

### **Natural History**

Cervical cancer is caused by Human Papillomavirus (HPV) which is a sexually transmitted infection. Persistent infection by high-risk HPV types is detectable in more than 99% of cervical cancers.<sup>5</sup> The majority of high-risk HPV infections are transient and cause no clinical problems. Within one year, around 70% of new infections will clear and approximately 90% of new infections will clear within two years.<sup>6,7</sup> However, persistent infection by a high-risk HPV type is the most important causal factor for the development of cervical neoplasia.

Cervical intraepithelial neoplasia 1 (CIN 1) is a histologic diagnosis associated with benign viral replication and in most cases spontaneously regresses. Studies in adult women show regression rates of 70-80% whereas in adolescents and young women they show more than 90% regression.<sup>8</sup>

Cervical intraepithelial neoplasia 2 (CIN 2) is a lesion which in some cases may progress to cancer, although many of these are known to regress. The annual regression rate of CIN 2 in adult women is estimated to range from 15%-23% with up to 55% regressing by 4-6 years.<sup>8</sup>

Cervical intraepithelial neoplasia 3 (CIN 3) has the greatest potential to progress to invasive cancer at the rate of 0.2% to 4% within 12 months. Progression times from CIN 3 to invasive carcinoma vary between 5 to 19 years.<sup>9,10,11</sup>

### **Risk Factors**

The risk factor for getting cervical cancer is persistent infection with high risk HPV. Smoking may increase the persistence of the virus: and having sexual intercourse at a young age, having many sexual partners and not using condoms increases the risk for getting HPV.

### **Age of first invitation for Cervical Screening**

In order to inform the individual country based policies literature syntheses have been produced. Appended here are the reviews carried out for the English cancer screening programmes by Peter Sasieni, Alejandra Castañón, and Jack Cuzick from the Wolfson Institute of Preventive Medicine. The BMJ also published the finding of a review done by the English cancer team soon after.<sup>12</sup> An unpublished review from Cervical Screening Wales, Public Health Wales is also attached.(Appendix 1)

### **Benefits and harms of screening women between 20 and 25 years**

Screening programmes should deliver more benefit than harm at a population level. The benefits of screening women aged between 20 and 25 years would be to identify cellular abnormalities that potentially could develop into cervical cancers; and to identify any cervical cancers that have already developed.

The harms of screening women this age are that normal cellular cervical changes in younger women may appear to be abnormal changes, leading to unnecessary treatment and potential anxiety for the woman. In some cases, treatment may lead to pre term delivery.

### **Number screened, number treated and number helped**

A flow chart to show the numbers invited, referred and treated is appended in Appendix 2

Outcome data for Wales shows that for the cohort of women aged 25 years as of 1<sup>st</sup> February 2011 (n=20,225) and invited to screening from age 20 years, there were 1,774 referrals following an abnormal smear results and 949 referrals resulting in treatment. In this cohort there were 522 cases of CIN3, 16 CGINs and 7 cancers diagnosed.

### **Anxiety**

It is reported in the literature that women who receive an abnormal smear result have increased anxiety, and their worries include fear that they have cancer, self blame, sexual guilt and concerns about infertility<sup>13</sup>. Most research has been on high grade abnormal smears however a study looking at 3500 women recruited to Tombola (trial of management of borderline and other low grade abnormal smear) found that women reported anxiety levels for low grade abnormal smear results which were consistent with those found in previous studies of women with high grade abnormal smear results. Stratification of the effect of age on anxiety was not discussed in any of the identified studies. But it is known that borderline and low grade abnormalities are found in higher proportions in younger women, so anxiety created by those conditions is likely to be more prevalent in younger women participating in screening than in an older population

Also there were no studies identified that discussed the effect of different policies across the UK on age of invitation, as young women may have been anxious especially following media attention on the death of a celebrity from cervical cancer.

### **Premature birth**

The relation between cervical cancer treatment and pre-term delivery has been debated. The following is from the Welsh report and summarises the position. For women in this age group there is concern about the possible impact on colposcopic interventions for future pregnancies. In a critical review of the literature published by the NHS Cervical Screening Programme<sup>17</sup> conflicting results from studies were reported. In 2007 a systematic review and meta analysis<sup>14</sup> of 27 studies found that LLETZ was significantly associated with preterm delivery with an overall Relative Risk of 1.70 (95% CI 1.24 - 2.35). In the five further primary research studies conducted after the meta analysis four

found that treatment was associated with an increased risk of preterm delivery and one found that the diagnosis of CIN3 was associated with preterm delivery and not treatment itself<sup>15</sup>. The majority of studies have been limited in their ability to take into account potential confounding factors that could be independently associated with being referred for colposcopy and preterm delivery for example maternal smoking, socioeconomic status and previous obstetric history.

## **Frequency of screening for women aged 50 to 64 years**

The screening interval for a screening programme needs to be based on the natural history of the disease in that population.

The evidence on which the screening interval was based was originally an international study conducted by the IARC that estimated yearly screening reduced the incidence of invasive cervical cancer by 94%, three yearly by 91%; five yearly by 84% and 10 yearly by 64%.<sup>16</sup> In 2003 two studies were published which provided more evidence on screening frequency. The first paper<sup>1</sup> analysed screening histories of 1305 women aged 20-69 years, diagnosed with frankly invasive cervical cancer and 2532 age matched controls obtained from the UK screening programme database. Their analysis showed that by using time since the last operationally negative cytological smear 4.5 to 5.5 yearly screening offered 72% (95% CI 43%-86%) protection compared to 2.5-3.5 yearly screening protection of 85% (95% CI 74%-92%) for women aged 55-69 for frankly invasive cervical cancer.

The authors produced summary point estimates of protection and concluded that five yearly screening offered similar protection to 3 yearly. The results of this paper informed England's decision to standardise to inviting women aged 50-64 years every 5 yearly. This paper has age groups in 55-69 and the policy is 50 -64 to allow time from screening to cancer diagnosis. The issues are that the paper assumed that screening to cancer diagnosis does not vary by age from 50 to 55 years, the analysis did not include screen detected micro invasive cancers; there were 490 (18%) results that had cancer stage unknown which may have biased the results, and the data was from England and the population in Wales may be different.

A Dutch study published in 2004<sup>17</sup> supported a five year screening interval by reporting that the incidence of squamous cell carcinoma and precursor lesions remained stable when changing from a 3 year to 5 year screening interval. However this study did not stratify the results by age.

Unpublished work undertaken by Sasieni *et al* and Cervical Screening Wales explored the effectiveness of the screening programme in Wales between 1999 and 2007. The odds ratio for screening between 1990 and 2001 were compared to those between 1999 and 2007 and population attributable risks were calculated. A total of 1,466 cases of cervical cancer were diagnosed in Wales between 1999 and 2007, 73% of which were diagnosed in women aged 20-64 years. There was no evidence to suggest that extending the screening interval from 3 yearly to 5 yearly in women aged over 50 years increased the risk of developing cervical cancer (OR 0.17, 95% CI 0.11- 0.27 vs, OR 0.14 95% CI 0.08-0.24 respectively).

## **HPV**

The NHS Cervical Screening Programme in England will begin incorporating HPV triage and Test of Cure into their screening programme this year. The sentinel site implementation project tested samples from women which contained cells with low-grade abnormalities (borderline or mild dyskaryosis). If they tested positive for high-risk HPV strains the women were referred for colposcopy and if they were negative for high risk HPV strains the women could be returned to routine recall.

The Scottish group convened to discuss the issue agreed to recommend that the lower age for screening in the Scottish Cervical Screening Programme be increased from 20 to 25. It was considered prudent to delay this increase in the lower age range until the HPV school vaccination programme is fully implemented and so implementation should be fully completed by 2015.

## Summary

That the UKNSC recommend that

- The age of first invitation for cervical screening be raised to 25 in Wales and Scotland on the basis that there is evidence of a large number of women screened and treated with relatively little benefit below this age.
- Screening for women aged 50-64 is undertaken five yearly.

Anne Mackie September 2012

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<sup>1</sup> Sasieni P, Adams J, Cuzick, J. Benefit of cervical screening at different ages: evidence from the UK audit of screening histories. *British Journal of Cancer* 2003; **89**:88-93.

<sup>2</sup> <http://www.cancerscreening.nhs.uk/cervical/faq08.html>

<sup>3</sup> Department of Health, Social Services and Public Safety. Letter HSS (MD)28/2010 Cervical screening programme- changes to the age to commence screening and screening interval. Available at: [www.dhsspsni.gov.uk](http://www.dhsspsni.gov.uk)

<sup>4</sup> Department of Health. Ministerial Statement. Cervical screening for women aged under 25 years. Published 24 June 2009 Available at: <http://www.cancerscreening.nhs.uk/cervical/news/0/12.html>

<sup>5</sup> Munoz N, Castellsague X, de Gonzalez AB *et al*. Chapter 1: HPV in the etiology of human cancer 2006; *Vaccine* **24** :S1-S10.

<sup>6</sup> Ho GY, Bierman R, Beardsley L *et al*. Natural history of cervicovaginal papillomavirus infection in young women. *N Engl J Med* 1998; **338**: 423-8.

<sup>7</sup> Franco EL, Villa LL, Sobrinho JP *et al*. Epidemiology of acquisition and clearance of cervical human papillomavirus infection in women from a high-risk area for cervical cancer. *J Infect Dis* 1999; **180**: 1415-23.

- 
- <sup>8</sup> Moscicki AB, Ma Y, Wibbelsman C et al. Rate of and risks for regression of cervical intraepithelial neoplasia 2 in Adolescents and young Women. *Obstetrics and Gynecology* 2010. **116**; 1373-1380.
- <sup>9</sup> McIndoe WA et al. The invasive potential of carcinoma in situ of the cervix. *Am J Obstet Gynecol* 1984. **64**: 451-458
- <sup>10</sup> Peterson D. Spontaneous course of cervical pre-cancerous conditions. *Am J Obstet Gynecol* 1956; **72**: 1062-1071
- <sup>11</sup> Gad D. The management and natural history of sever dysplasia and carcinoma in situ of the uterine cervix. *Br J Obstet Gynaecol* 1976; **83**: 554-559
- <sup>12</sup> Sasieni P, Castañónm A, Cuzick J. Effectiveness of cervical screening with age: population based case-control study of prospectively recorded data *BMJ* 2009; 339:b2968
- <sup>13</sup> Gray NM, sharp L, Coton SC et al. Psychological effects of a low-grade abnormal cervical smear test result: anxiety and associated factors. *British Journal of Cancer* 2006. **94**; 1253-1262.
- <sup>14</sup> Kyrgiou M, Koliopoulos G, Martin Hirsch P et al. Obstetric outcomes after conservative treatment for intraepithelial or early invasive cervical lesions: Sytematic review and meta-analysis. *Lancet*, 2006, **367**:489-498
- <sup>15</sup> Sasieni, P, Castanon, A, and Cuzick, J. The impact of cervical screening on young women:A critical review of the literature. Sheffield: NHS Cancer Screening Programme, 2010. Available at: <http://www.cancerscreening.nhs.uk/cervical/publications/nhscsp31.html>
- <sup>16</sup> IARC Working Group on Evaluation of Cervical cancer Screening Programmes. Screening for squamous cervical cancer: duration of low risk after negative results of cervical cytology and its implication for screening policies *BMJ* 1986 293 659-64.
- <sup>17</sup> Siemens FC, Boon ME et al Population-based cervical screening with a 5-year interval in the Netherlands. *Acta Cytologica* 2004 **48** 348-54

**UK National Screening Committee (UK NSC)**  
**Note of the meeting held on 13 November 2012**  
**at**  
**The Scottish Government, Room 4ER, St Andrew's House,**  
**Regent Road, Edinburgh, EH1 3DG**

**Present**

Sir Harry Burns (Chair)  
Dr Eric Baijal  
Dr Margaret Boyle  
Mrs Clare Brassington  
Ms Alison Brown  
Dr Catherine Calderwood  
Professor Alan Cameron  
Dr Jennie Carpenter  
Professor Gareth Evans  
Dr Rosemary Fox  
Dr Nick Hicks  
Mrs Madeleine Johnson  
Mr Nick Johnstone-Waddell  
Dr Surendra Kumar  
Dr Janet Little  
Dr Anne Mackie  
Dr Gordon Paterson  
Ms Cheryl Paris  
Dr Heather Payne

**Visitors**

Mr Tim Elliott (by tele-conference)  
Miss Laura Grainger  
Mr John Marshall  
Professor Catherine Peckham  
Professor Robert Steele

**Secretariat**

Miss Jo Taylor  
Miss Kathryn Flynn

**Apologies**

Ms Alex Berry  
Dr Sunil Bhanot  
Professor Roger Brownsword  
Professor Martin Buxton  
Ms Majella Byrne  
Dr David Elliman  
Ms Jane Fisher  
Mrs Moira Morris  
Professor Julietta Patnick  
Dr David Walker

## **Welcome and Introductions**

1.0 Sir Harry Burns welcomed all to the meeting including:-

### **New UK NSC Members**

- Dr Eric Baijal, Joint Director of Public Health, NHS Borders who will be replacing Dr Lesley Wilkie on the committee.
- Ms Alison Brown, who will be giving a consumer's perspective on screening to the committee.
- Dr Heather Payne who will be replacing Dr Jane Wilkinson as the Welsh Government's representative on the committee.

### **Agenda Item Presenters**

- Professor Catherine Peckham CBE, Programme Director, NHS Infectious Diseases in Pregnancy Screening Programme, presenting the antenatal screening for Human T-Cell Lymphotropic Virus-1 agenda item.
- Mr John Marshall, UK NSC Projects and Programmes Manager, presenting the antenatal screening for group B streptococcus carriage, antenatal screening for foeto-maternal alloimmune thrombocytopenia and newborn screening for kernicterus agenda items.
- Professor Robert Steele, University of Dundee and Mr Tim Elliott, Cancer Policy Team, Department of Health, presenting the bowel screening using flexible sigmoidoscopy agenda item.

### **Observer**

- Miss Laura Grainger, shadowing Miss Josephine Taylor as part of the NHS Management Programme.

## **2.0 Minutes and Matters arising**

2.1 The minutes of the last meeting were agreed.

2.2 There were ten actions points from the last meeting. Most were picked up as main agenda items. In addition:

### 1.2 Vacancies

Ms Alison Brown had been appointed as the consumer representative on the committee.

### 4.12 Draft policy for HPV testing to alter follow up regimes in cervical cancer

The draft policy for Human Papilloma Virus (HPV) testing to alter follow up regimes in cervical cancer paper will be placed on the UK NSC website for consultation shortly.

#### 4.12 Draft policy for HPV testing to alter follow up regimes in cervical cancer

The draft policy for HPV as Primary Screen for Cervical Cancer paper will be placed on the UK NSC website for consultation shortly.

#### 4.24 Bowel Cancer Screening

The evaluation of the 'Be Clear On Cancer Campaign' will be brought to a future meeting.

#### 4.30 Bowel Cancer Screening

An evaluation of the faecal immunochemical test against the UK NSC criteria will be a future agenda item.

#### 5.20 Asymptomatic Bacteriuria Screening in Pregnancy Policy Position Statement

Mr John Marshall will write to the National Institute for Health and Clinical Excellence (NICE) and the Health Protection Agency (HPA) about the issues identified in the asymptomatic bacteriuria screening in pregnancy review shortly.

#### 5.35 Screening for Duchenne Muscular Dystrophy Policy Position Statement

Mr John Marshall will write to the All Party Parliamentary Group on Muscular Dystrophy shortly.

### **3.0 Director's Report Back**

3.1 Dr Mackie gave an update as follows:-

*Update on Newborn Screening for Maple Syrup Urine Disease (MSUD), Homocystinuria (pyridoxine unresponsive), Glutaric Aciduria Type I (GAI), Isovaleric Acidaemia (IVA) and Long-chain 3 - hydroxyacyl CoA dehydrogenase deficiency (LCHADD)*

3.2 The evaluation to investigate extending the Newborn Bloodspot Screening Programme to include the above five conditions began in July 2012. While the evaluation takes place screening is offered to the populations served by the screening laboratories in Leeds, Manchester, Sheffield, Birmingham, London (Guy's and St Thomas' and Great Ormond Street). The evaluation would end on 19 July 2013, however, funding has been secured to extend screening for the above conditions for a further year while data is collected, analysed and written up. To date there have been ten test positive results with five children receiving a screening positive result after further investigation. The completed evaluation will be brought back to a future meeting for discussion.

**Action: Dr Mackie to bring the completed evaluation to a future meeting**

### *Pulse Oximetry Screening for Critical Congenital Heart Defects*

- 3.3 Pulse oximetry is a well established, accurate, non-invasive test for objective quantification of hypoxaemia in sick babies. Recent studies (referenced in the UK NSC paper) have addressed the accuracy of pulse oximetry as a screen for critical congenital heart defects (CCHD) and further recommend this as an addition to the current screening in the antenatal and newborn screening programmes.
- 3.4 An evaluation of the extent of the value and cost effectiveness of including a pulse oximetry test in the NIPE Screening Programme concluded that given the significant mortality and morbidity impact of undiagnosed CCHD this was likely to be quite cost effective. However, uncertainty remained about the best way of incorporating pulse oximetry into the clinical examination.
- 3.5 The NIPE Programme Centre had worked with a clinical reference group to document a best practice pathway that includes pulse oximetry and will be consulting on the pathway over the next few months.
- 3.6 Members asked who would carry out the pulse oximetry test and whether there would be staffing implications for neonatal care departments. Dr Mackie said it was envisaged that midwives or NHS hearing screeners could carry out the test. She said the consultation on the pathway should help determine who should carry this role out and highlight any potential staffing problems.
- 3.7 The completed review of pulse oximetry screening for CCHD will be brought to the next meeting.

**Action: Dr Mackie to bring the pulse oximetry screening for CCHD review to the next meeting**

### *European Council Recommendation on Rare Diseases*

- 3.8 Dr Mackie informed members that the United Kingdom Plan for Rare Diseases consultation which closed in May had asked respondents to consider whether the UK NSC should take into account the benefit of screening in reducing the 'diagnostic odyssey' and in allowing informed choice for subsequent family planning. A copy of the summary of consultation responses to the question on screening had been shared in confidence with the UK NSC.
- 3.9 Members discussed the consultation responses included in the paper. Members were concerned about responses which suggested the UK NSC lacked transparency and appropriate patient representation. Members asked for it to be made clear that the UK NSC has a clear policy review process (<http://www.screening.nhs.uk/policyreview>), all policy reviews follow this process and involve a three month public consultation. Guidance entitled 'Engaging with the UK NSC's policy review process' has been produced for stakeholder groups, explaining the policy review process and how to make effective submissions to policy consultations. Patient and lay representatives are represented on the UK NSC, Fetal, Maternal and Child Health Co-

ordinating group and on all NHS Screening Programme advisory and steering committees such as the Bloodspot Screening Advisory Group in England.

- 3.10 Consultees had raised concerns about the lack of randomised controlled trials for rare diseases. The UK NSC's internationally recognised criteria for appraising the viability, effectiveness and appropriateness of a screening programme states that there should be evidence from high quality RCTs that the screening programme is effective in reducing mortality or morbidity. The UK NSC acknowledges that undertaking RCTs is problematic in some areas and acknowledges that evaluations such as the one currently taking place on newborn screening for MSUD, Homocystinuria (pyridoxine unresponsive), GA1, IVA and LCHADD could be used as evidence where RCTs are not feasible.
- 3.11 Members agreed that the current criteria allow for consideration regarding time to diagnosis. They further agreed that in the case of rare diseases reviewers of screening policy should take into account reduction of the diagnostic odyssey. Members felt that the rights of children and young people should be addressed when looking to answer these questions. Members agreed that when reviewing screening programmes against its criteria consideration of the value placed on the benefit and disbenefits should be clear and stated in the review of evidence.

#### **4.0 Fetal Maternal and Child Health Screening**

##### **Report from Fetal, Maternal and Child Health Co-ordinating Group**

- 4.1 Mrs Madeleine Johnson, Chair of the Fetal, Maternal and Child Health Co-ordinating Group (FMCH) said that there had been two meetings of the FMCH since the UK NSC had last met. These took place in July and November. The paper circulated to the UK NSC related to the July meeting only. Mrs Johnson reported that:-

##### *Policy review work*

- 4.2 Reviews for a number of conditions discussed at the July meeting of the FMCH are main agenda items for today's meeting. At November's meeting it was agreed that changes needed to be made to the antenatal screening for syphilis review and newborn screening for biotinidase deficiency review before they could open for public consultation.

##### *Newborn screening for sickle cell carriers*

- 4.3 A review of newborn screening for sickle cell carriers in Wales concluded that screening for sickle cell carrier status in the newborn does not meet the UK NSC criteria for a screening programme. The Wales Screening Committee and the Newborn Bloodspot Project Board would work with the English Sickle Cell and Thalassaemia Screening Programme to explore the potential of TMS to detect sickle cell disease with and without detecting carriers.

*NHS Fetal Anomaly Screening Programme (NHS FASP) 18 – 20 week standards*

- 4.4 A project to update the programme standards is ongoing. As part of this concern had been raised that scanning within the current screening window has generated an increasing rate of repeat scans. The rate of repeat scanning appeared to vary by both gestation and unit. A proposal on an alternative screening window from NHS FASP is expected in March.

*Second trimester serum screening for Trisomy 21 (T21) using the quadruple test*

- 4.5 There is currently no nationally recommended test for twin pregnancies presenting later than 14 weeks + 1 day. NHS FASP proposed extending the recommendation for singleton pregnancies, the quadruple test (maternal serum AFP, intact or free  $\beta$ hCG, inhibin A + oestriol), to the small group of women with twin pregnancies presenting in the second trimester. In discussions members said they would find it helpful if some of the Down's Syndrome Screening Quality Assurance Support Service's data could be published. More information on this issue was considered necessary and an updated paper is expected to be presented to the FMCH in March.

*Screening for T13 & T18*

- 4.6 A review in this area is currently being commissioned in collaboration with NHS FASP.

*Screening for Tay Sachs Disease, Canavan Disease and Familial Dysautonomia*

- 4.7 Solutions for Public Health reviewed the evidence for antenatal, newborn and adult carrier screening for the above three conditions earlier this year. The documents were available for consultation for three months from May 2012 on the UK NSC website. The consultation responses raised a number of complex issues and the FMCH felt it would be appropriate to hold a workshop in the new year to consider the issues raised by the reviews and the consultation responses prior to making a policy recommendation to the UK NSC.

*Rubella Susceptibility Screening in Pregnancy*

- 4.8 At the last UK NSC meeting members had agreed that screening for rubella susceptibility does not meet the UK NSC criteria for a screening programme. The UK NSC had agreed that the present arrangements for antenatal screening and post partum immunisation should continue until other arrangements are in place. The Joint Committee on Vaccination and Immunisation has agreed to work jointly with the UK NSC to look at alternative approaches to screening.
- 4.9 Members noted the FMCH update.

## **Antenatal Screening for Human T-Cell Lymphotropic Virus (HTLV-1) Policy Position Statement**

- 4.10 Professor Catherine Peckham presented this item. HTLV-1 screening had previously been reviewed in 2003 and the recommendation was that screening should not be offered. HTLV-1 infection is life-long and most infected individuals remain asymptomatic. However, after a long latent period a small but significant proportion of individuals infected with HTLV-1 develop serious neurological and lymphoproliferative disease.
- 4.11 Members discussed the consultation replies. Responses had been received from the HTLV Patients Forum and the National HTLV clinical service, the National Centre for Human Retrovirology based at St. Mary's Hospital NHS Trust. While both were critical of the review and its conclusion, much of the review's content was accepted.
- 4.12 The UK NSC agreed the policy position on antenatal screening for HTLV-1 as a national antenatal screening programme for HTLV-1 is not recommended because:
- The prevalence of infection is very low in the UK with limited data on prevalence in the defined risk groups
  - The risk of mother-to-child transmission is low and data on the long term consequences of infection lacking
  - There is no effective treatment
  - The impact of avoiding breastfeeding is uncertain
  - The negative impact of maternal diagnosis of HTLV-1 on the woman and her family must not be underestimated
- 4.13 The UK NSC agreed that the policy should be reviewed in three years' time unless there is significant new peer reviewed evidence in the meantime.
- 4.14 The UK NSC agreed that the National Centre for Human Retrovirology should be encouraged to approach specialised commissioners regarding work in high risk groups / areas.

**Action: Dr Mackie to write to the National Centre for Human Retrovirology**

## **Antenatal Screening for Group B Streptococcus Carriage Policy Position Statement**

- 4.15 Mr Marshall introduced this item. The last review in 2009 concluded that screening for group B streptococcus (GBS) carriage should not be offered to all pregnant women. The latest review undertaken by Bazian concluded that the evidence had not changed significantly in key areas. These included:
- the natural history of transmission of GBS from the intestine and the genital tract to the baby is poorly understood

- the rate of early onset GBS in the UK is comparable to those countries in which screening is recommended and benefits of screening are uncertain
- screening at 35 - 7 weeks will not impact on a significant burden of early onset GBS disease
- the test cannot distinguish between the majority of low risk women and the minority whose baby will be affected, this results in over-detection and over-treatment of a very large number of women at very low risk.

As such a change of policy was not recommended.

- 4.16 Mr Marshall said that the flow chart contained in the papers estimated that the introduction of a screening programme would prevent 5 -7 deaths in the newborn per year and between 17,000 - 25,000 women would receive antibiotics in labour to prevent 1 death. The consequences of expanding the use of antibiotics are unknown and there was concern about the long term effects on the newborn and the potential for anaphylactic reactions in labour.
- 4.17 In discussion members were clear that the loss of any baby was devastating and acknowledged that this came through clearly in the consultation responses. Members were concerned about the use of antibiotics. A submission to the consultation from Northern Ireland reported an audit in which there had been two confirmed cases of maternal anaphylaxis from penicillin during labour, one of whom died. A third case, thought to be an anaphylactic reaction had yet to be confirmed. Research interest was focusing on the long term effects of antibiotics on the newborn such as obesity and asthma. Members felt that the practical impact screening would have on the antenatal and postnatal pathway was an important dimension which did not come through fully in the review as it was not explored in the published literature.
- 4.18 Mr Marshall drew attention to the consultation responses, in particular the response from Group B Strep Support Group (GBSS). The group were concerned that the UK NSC is biased in its review and treatment of this issue, in particular that the UK NSC had not used a systematic review methodology. Members were clear that the methodology was consistent with that used for other screening reviews considered acceptable to stakeholders. Systematic reviewing in this context would have slowed down the process and incurred costs that couldn't be justified by the knowledge that would potentially be gained. Members did, however, agree that it would be helpful to expand the information on the UK NSC website on the methodology.
- 4.19 On the review process, members agreed that this had also been consistent with the publicised process and with many other reviews undertaken by the UK NSC. The consultation process was transparent, had taken account of a large number of publications including that supplied by GBSS and other stakeholders and there had been extensive consultation (including experts recommended by GBSS). The review had been consultative and that it had tried to incorporate the views of stakeholders where possible.

- 4.20 Following extensive discussion members agreed that the current policy should be retained. This is because there is insufficient evidence to demonstrate that the benefits to be gained from screening all pregnant women and treating those carrying the organism with intravenous antibiotics during labour would outweigh the harms. Members were however, unanimous in their view that action needs to be taken to improve the outcome for babies affected but until a more effective test could be found screening did not provide the tool to do this.
- 4.21 Members also considered that the paper was complicated and policy position statement was quite technical. It was agreed that work should be undertaken to simplify the terminology to make it easier to understand from a lay perspective. An accompanying Q&A would be helpful in this respect.

**Action: Mr Nick Waddell to produce Q&A and publish it on the UK NSC website**

- 4.22 Members also agreed that the following text should be added to the policy statement:

“The current UK rate of early onset GBS is comparable to that in countries in which screening is recommended. A significant burden of disease is found in risk groups whose management would not be affected by a screening programme. The ability of screening to significantly impact on mortality and long term morbidity caused by GBS is uncertain.

Systematic reviews of culture testing suggest that many screen positive women may no longer be carriers at the point of treatment. In the absence of a diagnostic test, current screening strategies are unable to distinguish between carriers whose babies will be affected by early onset GBS and those which would not. As a result many thousands of low risk women would receive intravenous antibiotic prophylaxis during labour. The consequences of expanding antibiotic usage in this way are unknown.”

- 4.23 A range of further follow up action was agreed for exploration with key stakeholders:
- the Director of Programmes’ office should work to develop a communications strategy to promote understanding of the policy, perhaps in collaboration with the Royal College of Obstetricians and Gynaecologists and NICE;
  - a detailed modelling exercise based on assumptions arising from the review could be considered;
  - a national surveillance study should be encouraged to generate up to date epidemiological data;
  - a review of issues relating to antibiotic use in pregnancy and labour should be commissioned given the evolving context of work on the microbiome and the National Perinatal Epidemiology Unit’s study of anaphylaxis in pregnancy and labour;
  - the possibility of natural history studies exploring vertical transmission of GBS and development of early onset GBS in the newborn;

- work should be undertaken with the HTA to explore the possibility of studies of rapid testing in high risk groups (for example prolonged rupture of the membranes or preterm deliveries) as a means of targeting antibiotics in these populations.

**Action: Dr Mackie to contact stakeholders about these actions**

### **Antenatal Screening for Feto-Maternal Alloimmune Thrombocytopenia (FMAIT) Policy Position Statement**

- 4.24 Mr Marshall presented this item. The previous review had recommended that screening should not be offered. Mr Marshall said screening would aim to prevent severely affected cases (eg intracranial haemorrhage and intrauterine fetal death) in first affected pregnancies.
- 4.25 Members discussed the consultation responses. Mr Marshall said a positive endorsement of the review and its conclusions was received from the British Committee for Standards in Haematology. Detailed comments were received from the NHS Blood and Transfusion Service and the National Perinatal Epidemiology Unit. Comments from these organisations had been taken account of in the review following consultation.
- 4.26 The UK NSC agreed the policy position on antenatal screening for FMAIT as a national antenatal screening programme for FMAIT is not recommended because:
- The incidence of the FMAIT, as a whole, is unclear and in addition the incidence of severely affected cases is unclear.
  - There is uncertainty about the long term clinical effects of FMAIT.
  - A suitable predictor of severely affected cases had not been identified and, consequently, a test which could identify pregnancies which would benefit from intervention was lacking.
  - There is a lack of a clear management strategy for anti HPA-1a women
- 4.27 The UK NSC agreed that the policy should be reviewed in three years' time unless there is significant new peer reviewed evidence in the meantime.

### **Newborn Screening for Kernicterus Policy Position Statement**

- 4.28 Mr Marshall presented this item. He stated that kernicterus is a very rare complication of neonatal unconjugated hyperbilirubinaemia. In kernicterus high levels of bilirubin cause brain damage leading to neurological symptoms such as hearing loss and cerebral palsy and can in some cases be fatal. Screening for hyperbilirubinaemia has been suggested as a means of preventing kernicterus. The UK NSC previously reviewed screening for kernicterus in 2006. More recently the US Preventive Services Task Force considered the condition in 2009 and concluded that there was insufficient evidence on the benefits and harms of screening to recommend its introduction.

- 4.29 NICE had published guidance on the management of jaundice and this recommends an approach to testing babies' bilirubin levels based on risk factors. These being: prematurity (<38 weeks), sibling with jaundice requiring phototherapy, maternal intention to breastfeed exclusively, jaundice in first 24 hours of life.
- 4.30 Members discussed the consultation responses. The responses received agreed with the screening review's provisional recommendation.
- 4.31 The UK NSC agreed the policy position on newborn screening for kernicterus as a national newborn screening programme for kernicterus is not recommended because:
- There is an uncertain correlation between hyperbilirubinaemia and bilirubin encephalopathy. The association is often mediated by underlying problems such as blood group / rhesus incompatibility, infection, G6PD deficiency. More generally the progression from raised bilirubin levels to kernicterus is not well understood. Some babies develop bilirubin encephalopathy without having hyperbilirubinaemia and some with severe hyperbilirubinaemia do not develop bilirubin encephalopathy.
  - There appears to be some good evidence that babies at risk of developing hyperbilirubinaemia can be reliably detected using risk factors and /or bilirubin measurement. But as a marker of risk these appear insufficient in predicting bilirubin encephalopathy.
  - There is insufficient evidence that phototherapy is effective in treating hyperbilirubinaemia with the aim of preventing severe hyperbilirubinaemia.
- 4.32 The UK NSC agreed that the policy should be reviewed in three years' time unless there is significant new peer reviewed evidence in the meantime.

### **Screening for Autistic Spectrum Disorders in Children Under 5 Policy Position Statement**

- 4.33 Dr Mackie presented this item. Dr Mackie said autism spectrum disorders (ASD) are complex developmental disorders, including autism, Asperger's syndrome and pervasive developmental disorders. The previous screening review had concluded that screening for autism should not be offered. Dr Mackie said Solutions for Public Health were asked to review publications from January 2005 – November 2010 for the current review. The review focused on issues relating to the test and the treatment.
- 4.34 Members discussed the consultation responses. Dr Mackie said the review had been revised following consultation to reflect the comments received.
- 4.35 The UK NSC agreed the policy position on screening for autism and autistic spectrum disorders in children under 5 as a national screening programme for autism and autism spectrum disorder in children under 5 is not recommended because:

- Studies of the natural history of these conditions indicate that about a third of children who are given a diagnosis of ‘autism’ at 20-23 months of age as a result of a screening programme, and up to a quarter of those identified as being within the broader category of ‘ASD’, are likely to lose these diagnostic labels by the age of four years. It is not clear whether these figures reflect the impact of early intervention (assuming it is effective) or over-diagnosis at 20-23 months of age.
- No approach to screening for ASD has demonstrated reasonable performance, in terms of both sensitivity and positive predictive value, in a general population screening study.
- Approaches to screening for ASD used in recent studies are not accepted by a substantial proportion of parents. Parents of between one third and one half of all children who failed the initial screening test dropped out of the screening process before it had completed. Whether an established screening programme staffed by clinicians would be more acceptable than the approach used in these research studies is unknown.
- The review identified only three RCTs of Early Intensive Behavioural Intervention / Applied Behaviour Analysis, in which a total of 100 children have been studied.
- The effect of early intensive behavioural intervention/applied behaviour analysis on outcomes varied across the three identified RCTs. The most consistent effect (in two RCTs) was an improvement in IQ. The duration of follow-up in the largest trial (Dawson et al 2010) was limited to two years.
- The review identified 11 RCTs of various focused behavioural interventions, most of which reported some benefit from intervention. However, only one of these studies involved more than 60 children, and in most of them the children were followed up for only one year or less.
- Whether the short-term effects reported in these RCTs lead to significant improvements later in childhood, or greater independence and improved vocational and social functioning in adulthood, is unknown.

4.36 The UK NSC agreed that the policy should be reviewed in three years’ time unless there is significant new peer reviewed evidence in the meantime.

### **Adolescent Idiopathic Scoliosis Screening Policy Position Statement**

4.37 Dr Mackie presented this item. The purpose of screening for AIS is to identify a cohort of children who would benefit from interventions to reduce progression to clinically significant scoliosis and to reduce the need for spinal surgery. The UK NSC last reviewed screening for scoliosis in 2006 and recommended that screening should not be offered.

4.38 Members discussed the response to the consultation from the Scoliosis Society.

4.39 The UK NSC agreed the policy position on screening for scoliosis as a national screening programme for scoliosis is not recommended because:

- The accuracy of the most commonly used test, the forward bend test, and its ability to predict progression to clinically significant scoliosis is

questionable. As the test is unable to consistently identify a group of children who would progress in this way, screening could lead to unnecessary follow up procedures such as x-ray with which harm is associated. Scoliosis requiring aggressive treatment is likely to be detected without screening.

- The treatment usually involves exercise, bracing and surgery or a combination of these approaches. In general, there was some evidence to suggest that these approaches in adolescence lead to health benefits in only a small proportion of cases. As the majority of screen detected cases would not progress to clinically significant scoliosis, screening could lead to unnecessary referrals and treatment.

4.40 The UK NSC agreed that the policy should be reviewed in three years' time unless there is significant new peer reviewed evidence in the meantime.

## **5.0 Adult Screening**

### **Prostate Cancer Screening**

- 5.1 Dr Mackie presented this item. Following the UK NSC meeting on 25 April 2012, Dr Mackie had asked the School of Health and Related Research (SchHARR) to re-calibrate their disease model to include the latest European Randomized Study on Screening for Prostate Cancer (ERSPC) results and other relevant literature of the effect of screening for prostate cancer on the incidence of prostate cancer and prostate cancer mortality. Dr Mackie had also requested an update of key parameters in the screening model (for example adverse events of treatment, utility values, costs) where there is significant new data.
- 5.2 Dr Mackie said SchHARR are currently in the process of redesigning the model as a cohort model of disease natural history. She also reported that SchHARR have carried out six searches for literature to inform the model parameters. SchHARR had been unable to complete the work in time for this meeting.
- 5.3 A revised prostate cancer screening model would be brought to the next meeting of the UK NSC.

**Action: Dr Mackie to bring SchHARR's revised prostate cancer screening model to the next UK NSC meeting**

### **Bowel Screening Using Flexible Sigmoidoscopy**

- 5.4 Mr Tim Elliott and Professor Robert Steele presented this item. Mr Elliott said following delays, the IT system to support the flexible sigmoidoscopy (FS) pilots in England is now under development, and is due to be delivered in March 2013, when the pilots will start. Having met all the criteria, six pilot sites have been identified. Up to 20 other sites have also been identified to become Wave 1 of roll-out sites from October 2013. The pilot and roll-out were therefore still on track to deliver the commitment of 60% coverage of FS screening across England by March 2015.

- 5.5 Professor Robert Steele gave a presentation on bowel screening in Scotland. A copy of the slides are available at Annex A. Professor Steele said that in Scotland men and women from the age of 50 are offered bowel screening using guaiac faecal occult blood testing (gFOBT). Professor Steele said following the UK NSC recommendation on 10 March 2011 that FS met the UK NSC criteria for a screening test, Scotland had been considering how and at what age to introduce FS. Professor Steele said funding had been secured to carry out either an evaluation or an RCT in Scotland on offering FS at around the age of 60 in addition to the current gFOBT screening programme.
- 5.6 Members discussed whether an evaluation or an RCT should take place. Members felt that more information could be gathered from an RCT and endorsed this approach. Professor Steele said the results of the RCT would be brought to a future meeting.

**Actions: The Scottish Government to bring the results of the RCT to a future meeting**

### **Breast Screening Review in England**

- 5.7 Mr Elliott presented this item. Mr Elliott reported that an independent review of breast cancer screening in England was published on 30<sup>th</sup> October 2012, along with an accompanying paper in *The Lancet*. The panel consisted of nationally and internationally recognised experts in epidemiology and/or medical statistics as well as in current breast cancer diagnosis and treatment practices. No panel member had previously published on breast screening. The independent panel concluded that:
- *Relative mortality*  
The panel's best estimate is a 20% reduction in mortality from breast cancer in women invited for screening.
  - *Absolute mortality benefit*  
Around one breast cancer death is prevented for every 200 women invited.
  - *Over-diagnosis*  
Around 20% of the cancers detected through breast screening may not have been a problem in the lifetimes of the women invited for screening.
  - *Lives saved*  
For the UK based breast screening programmes, the panel estimate that around 1,300 deaths are prevented each year (amounting to 22,000 years of life saved).
  - *Balance of harms and benefits*  
For every 10,000 women invited for breast screening between 50 and 70 years old, the panel estimate that 681 cancers will be diagnosed of which 129 will represent over-diagnosis, and 43 deaths from breast cancer

will be prevented. Thus three cases are over-diagnosed for every death prevented.

- 5.8 Mr Elliott said the Panel concluded that “the UK breast screening programmes confer significant benefit and should continue.” However, the panel also said “It is now vital to give women information that is clear and accessible before they go for a mammogram so they can understand both the potential harms and benefits of the process”.
- 5.9 Mr Elliott said the Panel’s review of the randomised trials of breast screening lead to recommendations about future research priorities. These were included in the meeting paper.
- 5.10 Mr Elliott said that, in light of their findings on overdiagnosis, the Panel had recommended a re-evaluation of the cost-effectiveness of the NHS breast cancer screening programme. Dr Mackie said Professor Martin Buxton had expressed an interest in this work, and that she would be discussing how best to take this work forward with Professor Julietta Patnick and Professor Sir Mike Richards.
- 5.11 Mr Elliott said a group had been established to advise on the revision of information for invitees and promoting informed choice across all the cancer screening programmes in England. Members asked if the leaflets could be written in lay persons terms so people can easily understand them and that the same information be adopted in all four UK countries.
- 5.12 The UK NSC noted the update

#### **Age of First Invitation for Cervical Screening and Frequency of Invitation for Women Aged Between 50 -64 Years**

- 5.13 Dr Mackie presented this item. Dr Mackie said age of commencement and frequency of invitation of cervical screening varies across the UK. The age ranges offered screening in each country is as follows:
- Wales - women aged 20-64 years are invited for screening every three years
  - Scotland - women aged 20-60 years are invited for screening every three years
  - England - women aged 25 – 49 are invited for screening every three years and every five years for those aged 50-64
  - Northern Ireland - women aged 25 – 49 are invited for screening every three years and every five years for those aged 50-64
- 5.14 Dr Mackie said the Welsh Screening Committee had asked the UK NSC for a definitive UK NSC policy on the age at which women should first be invited for cervical screening. Dr Mackie had carried out a screening review which had been open for consultation for three months from the 10 May 2012 until 10 August 2012.

- 5.15 Members discussed the thirty responses received to the consultation. The UK NSC received ten responses from NHS and professional organisations (mostly based in Wales). These organisations were supportive of the UK NSC's provisional recommendation. Of the seven responses from individual clinicians/professionals, one was supportive, five were not supportive and one didn't have a view. Concerns raised focused on the role of HPV vaccination and the need to consider the women who have not been vaccinated. The issue of increased sexual activity amongst young people was also raised as a reason to continue screening from 20, as well as the potential for sending mixed messages about the importance of early detection of cancer.
- 5.16 Three charities responded to the consultation. These were Cancer Research UK, Jo's Trust and the Mercedes Curnow Foundation. Cancer Research UK and Jo's Trust supported the UK NSC's provisional recommendation. The Mercedes Curnow Foundation did not agree with the provisional recommendation. They stated that some young symptomatic women are being missed as GPs are not always following the NHS clinical practice guidance. The ten individual members of the public who responded were critical of the recommendation, though there was some confusion about the purpose of offering screening and whether symptomatic women can or should receive a screening test. Other concerns expressed were that raising the age is just a cost-cutting exercise and that it is a violation of the human rights of women under 25 to deny them the choice of being screened. Members thanked all of the public who responded to the consultation, many of whom had shared their personal experiences with the UK NSC.
- 5.17 Dr Kumar asked whether there was any advice for GPs who received a request for a cervical screening test from a young woman under the age of 25 who was not symptomatic of cervical abnormalities. Mr Elliott said that the Advisory Committee on Cervical Screening in England had developed such guidance following the review of first screening age in England in 2009, which was available at:  
[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_113478](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113478). The guidance has been endorsed by the Royal College of Obstetricians and Gynaecologists, the Royal College of General Practitioners and the Royal College of Physicians.
- 5.18 The UK NSC agreed the policy position on screening for cervical abnormalities as a national cervical screening programme is recommended. The age of first invitation for cervical screening should be raised to 25 in Wales and Scotland on the basis that there is evidence of a large number of women screened and treated with relatively little benefit below this age. Screening for women aged 50-64 should be undertaken five yearly.
- 5.19 Members stated that if the Welsh Government and the Scottish Government accept the UK NSC's recommendation public awareness campaigns need to be put in place to ensure people find out about and understand the reasons for the changes to the cervical screening programmes.

**6.0 Updates (for information)**

These are for information only.

**6.1 MRC trials administered by Efficacy and Mechanism Evaluation (EME) Programme**

**6.2 HTA Update**

**6.3 SIGN Update**

**7.0 Any Other Business**

There was none.

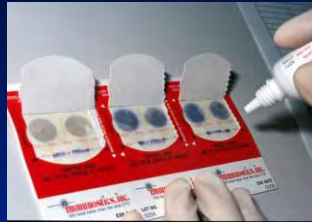
**8.0 Next Meeting**

Wednesday 20<sup>th</sup> March 2013  
11:30am – 3pm  
Royal Free Hampstead NHS Trust  
344 - 354 Gray's Inn Road  
London  
WC1X 8BP

## **Action Points**

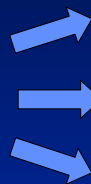
1. Dr Mackie to bring the completed evaluation of newborn screening for Maple Syrup Urine Disease (MSUD), Homocystinuria (pyridoxine unresponsive), Glutaric Aciduria Type I (GA1), Isovaleric Acidaemia (IVA) and Long-chain 3 - hydroxyacyl CoA dehydrogenase deficiency (LCHADD) to a future UK NSC meeting.
2. Dr Mackie to bring the pulse oximetry screening for CCHD review to the next meeting.
3. Dr Mackie to write to the National Centre for Human Retrovirology regarding approaching specialised commissioners about HTLV-1.
4. Mr Nick Waddell to produce Q&A on GBS and publish it on the UK NSC website.
5. Dr Mackie to contact stakeholders about the GBS action points.
6. Dr Mackie to bring SchARR's revised prostate cancer screening model to the next UK NSC meeting.
7. The Scottish Government to bring the results of the RCT on FS to a future UK NSC meeting.

## Guaiac FOBT Screening



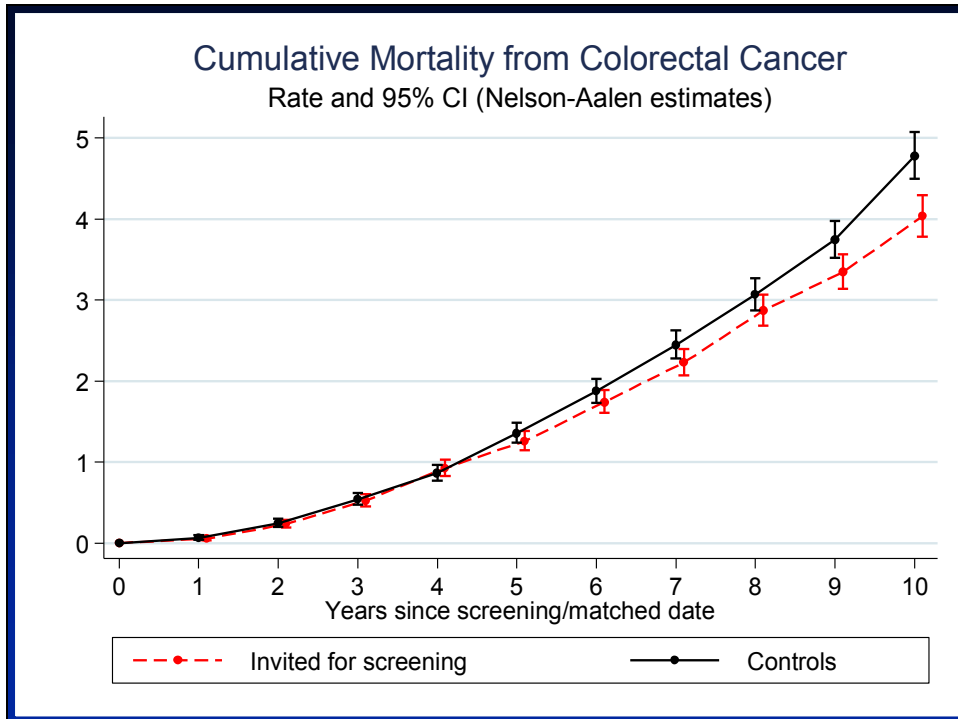
## Organisation of the bowel cancer screening programme - Scotland

### Single Centre



Investigation and treatment devolved to health boards (n=14)

Age range 50 - 74



## Rate ratio of Colorectal Cancer invited vs controls

### Overall

0.90 (0.830 – 0.989)

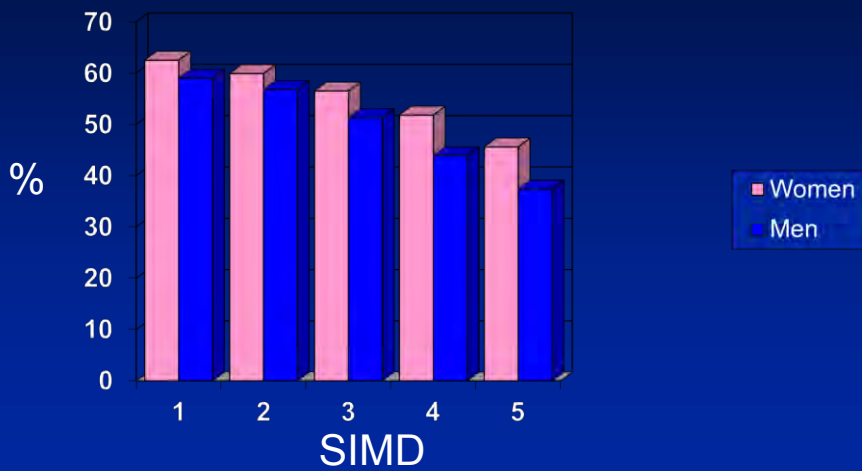
Relative reduction in CRC mortality 10%

### Participants only

0.73 (0.653 – 0.824)

Relative reduction in CRC mortality 27%

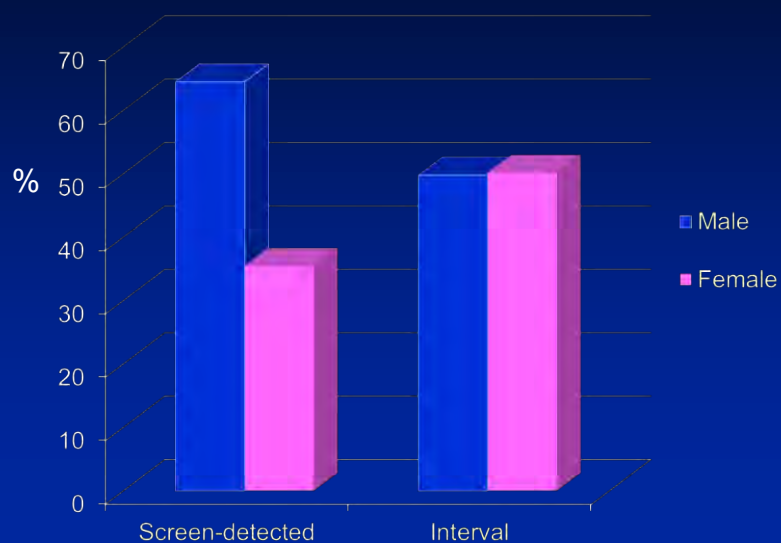
## Uptake - Gender and Deprivation



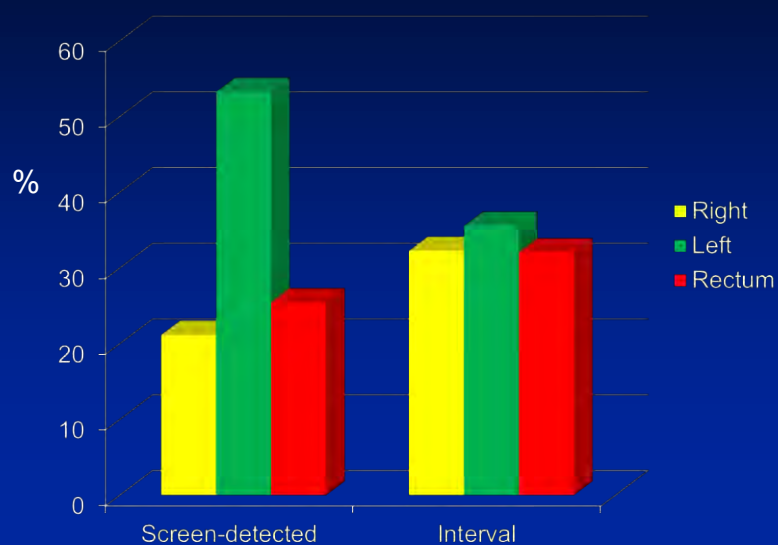
## Cancers Diagnosed in the Screened Population

	Round 1	Round 2	Round 3
Screen -detected	351 (56.6%)	208 (46.5%)	139 (35.7%)
<b>True interval</b>	<b>193</b> <b>(31.2%)</b>	<b>213</b> <b>(47.7%)</b>	<b>229</b> <b>(58.9%)</b>
Missed	2 (0.3%)	4 (0.9%)	2 (0.5%)
Miscellaneous	66 (10.7%)	22 (4.9%)	19 (4.9%)
Not on Socrates	6 (1%)	0	0

## Gender distribution - all rounds



## Site distribution - all rounds



## Issues to address

- Uptake
- Interval Cancers
  - Gender inequality
  - Rectal and right-sided cancers

## Uptake


- “User-friendly” tests
- “Teaser” letters
- Psychological interventions
- Early contact with health professional
- Better information
- GP involvement
- Publicity campaigns

## Interval Cancers

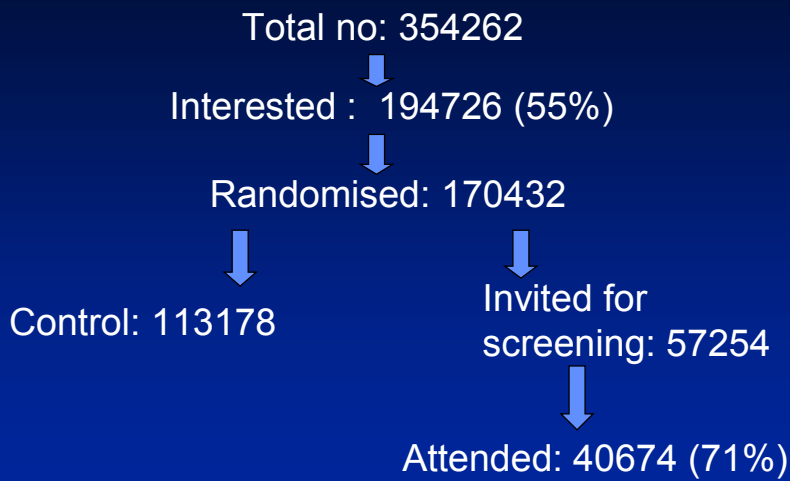
- Increase sensitivity of FOBT
  - Quantitative FIT
- Endoscopic screening
- Novel screening markers

## ICRF/MRC Study

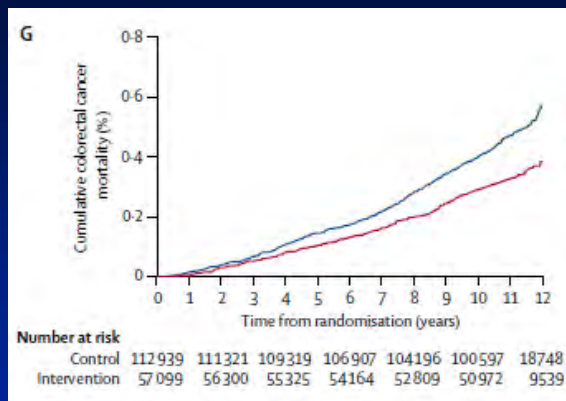
(Oct 1996 – March 1999)

- Single flexible sigmoidoscopy *with removal of adenomas*
  - 55-64 years
- High risk  colonoscopy
  - adenoma > 1cm
  - 3+ adenomas
  - tubulovillous or villous histology
  - 20+ hyperplastic polyps above distal rectum
  - cancer

# ICRF/MRC Study



## Mortality from CRC

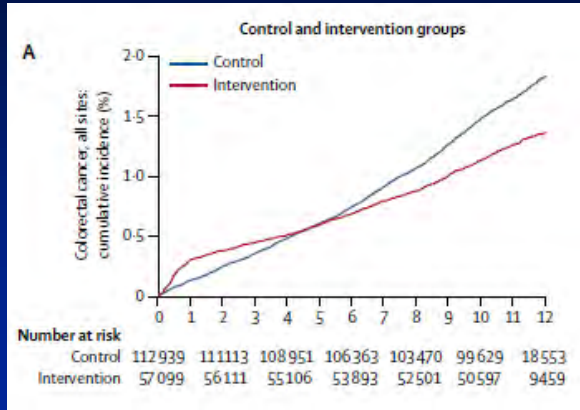


Once-only flexible sigmoidoscopy screening in prevention of colorectal cancer: a multicentre randomised controlled trial

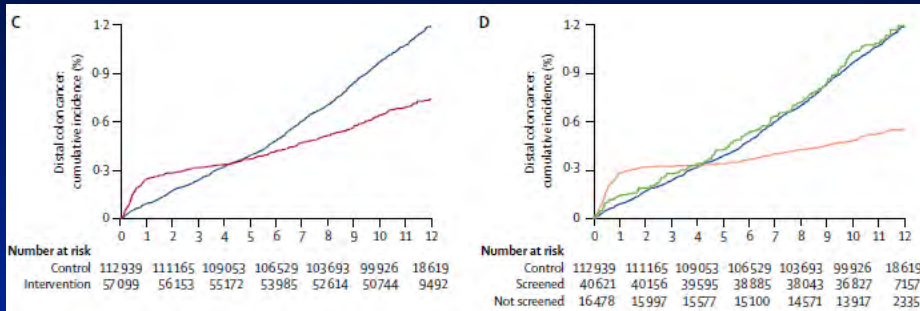
Wendy S Atkin, Rob Edwards, Ines Kralj-Hans, Kate Woodrige, Andrew R Hart, John M A Northover, D Max Parkin, Jane Wardle, Stephen W Duffy, Jack Czuzik, UK Flexible Sigmoidoscopy Trial Investigators

Published Online  
April 28, 2010  
DOI:10.1016/S0140-6736(10)60551-X

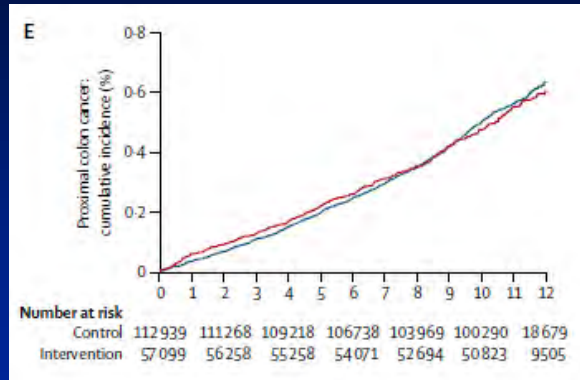
# Incidence of CRC



# Incidence of L-sided CRC



## Incidence of R-sided CRC



## Potential Advantages of FS

- Disease prevention
  - Enhanced detection of left-sided adenomas
- Detection of rectal cancer
- Unlikely to be a gender difference

## Potential Problems with FS

- Uptake
  - May be <30% (FS Study, Pathfinders)
  - Possibility of exaggerated deprivation gradient
- Effect on right-sided cancers

## Combination of FS and FOBT?

- FS
  - Enhanced screening for rectum and L colon
  - Prevention
- FOBT
  - “Safety net” for those who choose not to undergo FS
  - Detection of R-sided cancers

## Future of FS in Scotland?

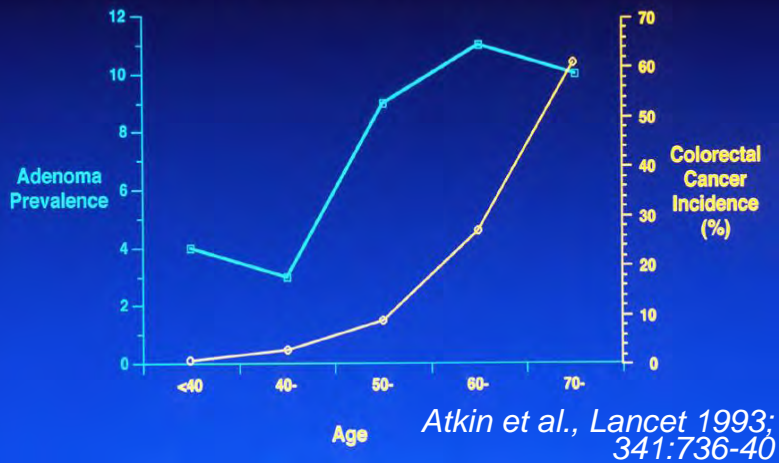
- Commitment to role out in England
  - At age 55 before FOBT screening starts
- Position in Scotland
  - FOBT screening starts at age 50
  - What is added value of FS in a population that has been offered FOBT?

## Questions

- Is FS screening feasible in Scotland?
- What is the uptake in an unselected Scottish population?
- What is the effect of gender and deprivation on uptake?
- What is the effect of offering FS on the overall uptake of screening?
- What is the added benefit in FOBT screened population?

## What is the ideal age for FS?

### Distal adenomas detected at screening by sigmoidoscopy vs. colorectal cancer incidence



## Proposal

- £2 m available
- Evaluation of FS offered at around the age of 60 *in addition* to current FOBT programme
- Greater Glasgow
  - Urban environment
  - High levels of deprivation
- Tayside
  - Mixed urban/rural environment
  - Well established FOBT screening

## Issues

- Invitation system
- Information
- Delivery of bowel prep
- Provision of FS
- QA of FS
- Data capture and analysis

## Numbers and Costs

- 8,000 FS - £1.6m
- 800 Colonoscopies - £200,000
- Pathology - £80,000
- Total £1.88m

## Evaluation or RCT?

- Evaluation
  - Proven screening technology
  - Fewer ethical issues
- RCT
  - Easier to estimate effect of adding FS

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# Comparison of screening from age 20 and age 25

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Table of harms and benefits

- The following table shows what would happen between ages 20 and 26 (inclusive) in terms of number of screens, women with abnormal test results, referrals to colposcopy and women treated per 100,000 women screened from age 20 compared to screening from age 25. It also includes estimates of the numbers of cancers (aged 20-29) in the two groups. We use published screening data from England and from Wales as well as cohort data from the NHSCSP audit of invasive cervical cancer.
- In the table the number of screening episodes and the number of non-negative test results are rounded to the nearest thousand. The number of referrals to colposcopy and the number of women treated are rounded to the nearest hundred.
- The figures are linked to explanations justifying each number.

Note: In the explanations of the figures we use rounded percentages. However, if we would have used the unrounded one, the resulting numbers are only slightly different so that the table of harms and benefits, which includes the rounded numbers to the nearest thousand or hundred, would be the same.

	Age group	100,000 women screened from age 20	100,000 women screened from age 25	Difference
<b>Screened</b>	20-24	<u>124,000</u>	<u>0</u>	
	25-26	<u>51,000</u>	<u>55,000</u>	
	Sum	175,000	55,000	<b>120,000</b>
<b>Non-negative test results</b>	20-24	<u>26,000</u>	<u>0</u>	
	25-26	<u>7,000</u>	<u>9,000</u>	
	Sum	34,000	9,000	<b>25,000</b>
<b>Referred to colposcopy</b>	20-24	<u>10,500</u>	<u>0</u>	
	25-26	<u>3,400</u>	<u>4,500</u>	
	Sum	13,900	4,500	<b>9,400</b>
<b>Treated (Excision, Ablation)</b>	20-24	<u>4,400</u>	<u>0</u>	
	25-26	<u>1,800</u>	<u>2,500</u>	
	Sum	6,200	2,500	<b>3,700</b>
<b>Cancers (stage 1A)</b>	20-24	<u>9</u>	<u>0</u>	
	25-29	<u>30</u>	<u>35</u>	
	Sum	39	35	<b>4</b>
<b>Cancers (stage 1B+)</b>	20-24	<u>11</u>	<u>13</u>	
	25-29	<u>45</u>	<u>47</u>	
	Sum	56	60	<b>-4</b>
<b>Cancers (All)</b>	20-24	20	13	
	25-29	75	82	
	Sum	95	95	<b>0</b>

## Number of screening episodes between ages 20 and 24 assuming 100,000 women are invited three-yearly from age 20

- 124,000 is based on the number of women aged 20-24 screened in the financial year 2010/11 in Wales. In that year 26,836 [Table 8a, Wales 2010-11\*] women had at least one adequate screening test out of a population of 107,870 [Table 1, Wales 2010-11\*]. Multiplying by five, we estimate the number of screening episodes to be **124,390**.



## Number of screening episodes between ages 25 and 26 assuming 100,000 women are invited three-yearly from age 20

- 51,000 is based on the number of women aged 25-29 screened in the financial year 2010/11 in Wales. In that year 25,104 [Table 8a, Wales 2010-11\*] women had at least one adequate screening test out of a population of 98,908 [Table 1, Wales 2010-11\*]. Multiplying by two, we estimate the number of screening episodes to be **50,762**.



Number of screening episodes between ages 20 and 24  
assuming 100,000 women are invited three-yearly from age 25

- This number is assumed to be **zero** because even if some women are screened from age 20, this by definition will be outside of the screening programme.



## Number of screening episodes between ages 25 and 26 assuming 100,000 women are invited three-yearly from age 25

- 55,000 is based on the number of women aged 25-29 screened in the financial year 2010/11 in England. In that year 543,316 [Table 8, England 2010-11\*\*] women had at least one adequate screening test out of a population of 1,976,700 [Table 2, England 2010-11\*\*]. Multiplying by two, we estimate the number of screening episodes to be **54,972**.

There is little data on whether the numbers screened aged 25-29 would be affected by the age of first invitation. Since the numbers screened per 100,000 are slightly higher in England than Wales, we use the figure for England here because (i) screening does now start from age 25 in England and (ii) these data result in a smaller difference in the total numbers of screening episodes from age 20 to 26 using the two strategies.

\*\* Cervical Screening Programme – England, 2010-11: Report is available on <http://www.ic.nhs.uk/>



## Number of non-negative test results between ages 20 and 24 assuming 100,000 women are invited three-yearly from age 20

- The number of non-negative tests results is obtained by multiplying the number of screening episodes by the proportion of women with a non-negative (borderline changes or worse) test in the year.
- Based on data for women aged 20-24 in Wales in 2010/11, 21.1% (5,662) of those (26,836) with an adequate test had a non-negative result [Table 8a, Wales 2010-11\*].

Multiplying the number of screening episodes between ages 20 and 24 (124,390) by 21.1%, we estimate the number of non-negative test results to be **26,246**.



## Number of non-negative test results between ages 25 and 26 assuming 100,000 women are invited three-yearly from age 20

- The number of non-negative tests results is obtained by multiplying the number of screening episodes by the proportion of women with a non-negative (borderline changes or worse) test in the year.

Based on data for women aged 25-29 in Wales in 2010/11, 14.5% (3,631) of those (25,104) with an adequate test had a non-negative result [Table 8a, Wales 2010-11\*].

- Multiplying the number of screening episodes between ages 25 and 26 (50,762) by 14.5%, we estimate the number of non-negative test results to be **7360**.

\* Cervical Screening Programme – Wales, 2010-11: Report is available on <http://www.screeningservices.org.uk/>



# Number of non-negative test results between ages 25 and 26 assuming 100,000 women are invited three-yearly from age 25

- The number of non-negative tests results is obtained by multiplying the number of screening episodes by the proportion of women with a non-negative (borderline changes or worse) test in the year.
- Among the controls in the national audit of cervical screening [Audit England 2011#], it is observed that the proportion of screening tests that are borderline or mild is about 10% greater among women not screened in the previous 3-5 years compared to among women screened 3-5 years earlier. Similarly the proportion of moderate or worse cytology was about 35% greater (for details see [here](#)).
- Based on data for women aged 25-29 in England in 2010/11, 13.1% (71,022) of those (543,316) with an adequate test had a non-negative result [Table 8, England 2010-11\*\*]. Since the proportion of non-negative tests is less in England than in Wales, we use instead, the proportion from Wales in order to minimise our estimate of the difference in the number of non-negative tests between the two scenarios.  
In Wales the proportion of borderline and mild test in women aged 25-29 was 11.2% (2,812 of those 25,104 with an adequate test result [Table 8a, Wales 2010-11\*] ) and the proportion of moderate or worse was 3.3% (819 of those 25,104 with an adequate test result [Table 8a, Wales 2010-11\*] ).  
The proportion of non-negative tests aged 25-26 in women not screened previously is thus estimated as  $11.2\% * 1.1 + 3.3\% * 1.35 = 16.8\%$ .
- Applying this to the number of women screened aged 25-26, yields **9,235** women with a non-negative test.

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\* Cervical Screening Programme – Wales, 2010-11: Report is available on <http://www.screeningservices.org.uk/>

\*\* Cervical Screening Programme – England, 2010-11: Report is available on <http://www.ic.nhs.uk/>

# NHSCSP audit of invasive cervical cancer, National Report 2007-2010, published July 2011: Report is available on <http://www.cancerscreening.nhs.uk/>



# Relative risk of abnormal test result at age 25-26 in those first screened at 25-26 compared to those also screened aged 20-24

- The analysis is based on population controls born on or after 1 January 1968.
  - There were 1189 control women with an adequate cytology result at age 25 or 26 (actually aged between 24.67 and 27.33) who did not have a cytology test between aged 20-24 (actually 19.67-24.67 nor within 5.5 years of their first test after age 24.67). The results of their first such test are recorded in the table.
- The first adequate result after a gap of at least 2.5 years for 2902 women aged 25-26 years, who also had an adequate cytology result aged 20-24 (actually between 19.67 and 24.67) is tabulated too.
- The group not screened aged 20-24, had a relative risk of low-grade cytology at age 25-26 of 1.09 (95% CI: 0.87 to 1.37) compared to those screened age 20-24. Similarly for a high-grade cytology result the relative risk was 1.34 (0.88 to 2.04). Adjustment for region of the country and/or calendar year of the test made little difference. For convenience we round the relative risks to 1.10 and 1.35 respectively.

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	Not screened 20-24	Screened 20-24	Relative Risk	95% CI
Normal	1055	2616		
Low-grade	101 (8.5%)	226 (7.8%)	1.09	(0.87-1.37)
High grade	33 (2.8%)	60 (2.1%)	1.34	(0.88-2.04)
Total	1189	2902		



## Number of referrals to colposcopy between ages 20 and 24 assuming 100,000 women are invited three-yearly from age 20

- The numbers referred to colposcopy are estimated assuming that all women with moderate or worse dyskaryosis and that 30.8% of women with borderline or mild dyskaryosis are referred.
- The figure 30.8% is based on an average of data from Wales and England (for details see [here](#)).
- Based on data for women aged 20-24 in Wales in 2010/11, 18.3% (4,904) of those (26,836) with an adequate test had a borderline or mild result and 2.8% (758) of those (26,836) with an adequate test had a moderate or worse result [Table 8a, Wales 2010-11\*]. Thus, we estimate the number of moderate and worse to be  $2.8\% \times 124,390 = 3,483$  and the number of borderline and mild to be  $18.3\% \times 124,390 = 22,763$ . Of the latter,  $30.8\% = 7,011$  will be referred, yielding a total number referred of **10,494**.



## Number of referrals to colposcopy between ages 25 and 26 assuming 100,000 women are invited three-yearly from age 20

- The numbers referred to colposcopy are estimated assuming that all women with moderate or worse dyskaryosis and that 30.8% of women with borderline or mild dyskaryosis are referred.

The figure 30.8% is based on an average of data from Wales and England (for details see [here](#)).

Based on data for women aged 25-29 in Wales in 2010/11, 11.2% (2,812) of those (25,104) with an adequate test had a borderline or mild result and 3.3% (819) of those (25,104) with an adequate test had a moderate or worse result [Table 8a, Wales 2010-11\*]. Thus, we estimate the number of moderate and worse to be  $3.3\% \times 50,762 = 1,675$  and the number of borderline and mild to be  $11.2\% \times 50,762 = 5,685$ . Of the latter,  $30.8\% = 1,751$  will be referred, yielding a total number referred of **3,426**.

\* Cervical Screening Programme – Wales, 2010-11: Report is available on <http://www.screeningservices.org.uk/>



## Number of referrals to colposcopy between ages 25 and 26 assuming 100,000 women are invited three-yearly from age 25

- The numbers referred to colposcopy are estimated assuming that all women with moderate or worse dyskaryosis and that 30.8% of women with borderline or mild dyskaryosis are referred.
- The figure 30.8% is based on an average of data from Wales and England (for details see [here](#)).
- Based on earlier assumptions (see [here](#)), the number of moderate and worse was  $3.3\% \times 1.35 \times 54,972 = 2,449$  and the number of borderline and mild was  $11.2\% \times 1.1 \times 54,972 = 6,773$ . Of the latter, 30.8% = 2,086 will be referred, yielding a total number referred of **4,535**.



# Referral proportion of women with a borderline or mild test result

- In Wales there were 7,454 women referred to colposcopy considering only the women with referral indication borderline, mild, moderate or worse [Table 16a, Wales 2010-11\*] and 3,161 who had a moderate or worse result based on the most significant test result [Table 8a, Wales 2010-11\*]. By subtraction there were 4,293 referrals following a lesser abnormality. In total there were 15,292 women whose most significant test result was borderline or mild [Table 8a, Wales 2010-11\*]. Thus, the referral proportion is 28.07%. Including the group of women who had a referral due to an inadequate or negative test result, there were 7671 women referred to colposcopy [Table 16a, Wales 2010-11\*] and therefore, 4,510 (=7,671-3,161) referrals due to lesser abnormality. For this scenario the proportion of referrals is 29.49%.  
In England there were 105,236 women referred to colposcopy considering only the women with referral indication borderline, mild, moderate and worse [Table 20, England 2010-11\*\*] and 42,076 who had a moderate or worse result based on the most significant test result [Table 8, England 2010-11\*\*]. By subtraction there were 63,160 referrals following a lesser abnormality. In total there were 188,126 women whose most significant test result was borderline or mild [Table 8, England 2010-11\*\*]. Thus, the referral proportion is 33.57%. Including the group of women who had a referral due to an inadequate result (referrals due to a negative test result were not considered in England), there were 107,381 women referred to colposcopy [Table 20, England 2010-11\*\*] and therefore, 63,305 (=107,381-42,076) referrals due to lesser abnormality. For this scenario the proportion of referrals is 33.65%.
- The women who are referred due to an inadequate or negative test result are considered as a special group. Women are only referred after three inadequate test results and women with a negative result are referred for other clinical reasons. Since we base the table on the most significant result in year, where the tests classified as inadequate were excluded, we take the average of the referral proportions from Wales and England excluding the women who had a referral due to an inadequate or negative test result. This leads to a referral proportion of women with a borderline or mild result of **30.8%** (= (28.07%+33.57%)/2). However, including these women the proportions are only slightly different because the amount of women referred to colposcopy due to an inadequate or negative results is very low (0.64% due to an inadequate and 2.2% due to a negative result in Wales [Table 16a, Wales 2010-11\*] and 1.5% due to an inadequate result in England [Table 20, England 2010-11\*\*] ). Since there are no data by age, we assume that the referral proportion is the same at all ages.

\* Cervical Screening Programme – Wales, 2010-11: Report is available on <http://www.screeningservices.org.uk/>

\*\* Cervical Screening Programme – England, 2010-11: Report is available on <http://www.ic.nhs.uk/>



# Number of women treated between ages 20 and 24 assuming 100,000 women are invited three-yearly from age 20

- There is not good data on the numbers of women treated. We assume that the number treated is the same as the number with CIN2 or worse on histology. Since there are no data on histology outcome by age, we assume that the positive predictive value of cytology for CIN2+ is the same at all ages.
- In Wales 85.5% of women with moderate or worse dyskaryosis have CIN2 or worse on histology [Table 14d, Wales 2010-11\*]. In England the figure is 83.0% [Table 18, England 2010-11\*\*]. We use 84% in these calculations, which is an average of the proportions in Wales and England.
- In Wales 24.9% of women referred with less than moderate dyskaryosis have CIN2 or worse on histology [Table 14b, Wales 2010-11\*]. In England the figure is 17.4% [Table 18, England 2010-11\*\*]. We use 21% in these calculations, which is an average of the proportions in Wales and England.

Based on data for women aged 20-24 in Wales in 2010/11, 18.3% (4,904) of those (26,836) with an adequate test had a borderline or mild result and 2.8% (758) of those (26,836) with an adequate test had a moderate or worse result [Table 8a, Wales 2010-11\*]. Thus, we estimate the number of moderate and worse to be  $2.8\% \times 124,390 = 3,483$  and of the latter,  $84\% = 2,926$  will be treated. The number of referrals due to a borderline and mild test result is  $30.8\% \times 18.3\% \times 124,390 = 7,011$ . Of the latter,  $21\% = 1,472$  will be treated, yielding a total number treated of **4,398**.

- There are also data on the rates of CIN3 registered in women aged 20-24. In Scotland, the rates in 2008 were 359 per 100,000 (461 aged 25-29). Over 5-years this would yield 1,795 per 100,000. If only 50% of treated women have CIN3 (with the rest having CIN2 or less), then it is reasonable to estimate the number treated to be around 3500. This is slightly lower than the figure we use, but it is based on data from Scotland due to a lack of data from Wales.

\* Cervical Screening Programme – Wales, 2010-11: Report is available on <http://www.screeningservices.org.uk/>

\*\* Cervical Screening Programme – England, 2010-11: Report is available on <http://www.ic.nhs.uk/>



# Number of women treated between ages 25 and 26 assuming 100,000 women are invited three-yearly from age 20

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- Based on data for women aged 25-29 in Wales in 2010/11, 11.2% (2,812) of those (25,104) with an adequate test had a borderline or mild result and 3.3% (819) of those (25,104) with an adequate test had a moderate or worse result [Table 8a, Wales 2010-11\*]. Thus, we estimate the number of moderate and worse to be  $3.3\% \times 50,762 = 1,675$  and of the latter,  $84\% = 1,407$  will be treated. The number of referrals due to a borderline and mild test result is  $30.8\% \times 11.2\% \times 50,762 = 1,751$ . Of the latter,  $21\% = 368$  will be treated, yielding a total number treated of **1,775**.

\* Cervical Screening Programme – Wales, 2010-11: Report is available on <http://www.screeningservices.org.uk/>

\*\* Cervical Screening Programme – England, 2010-11: Report is available on <http://www.ic.nhs.uk/>



## Number of women treated between ages 25 and 26 assuming 100,000 women are invited three-yearly from age 25

- There is not good data on the numbers of women treated. We assume that the number treated is the same as the number with CIN2 or worse on histology. Since there are no data on histology outcome by age, we assume that the positive predictive value of cytology for CIN2+ is the same at all ages.
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- In Wales 24.9% of women referred with less than moderate dyskaryosis have CIN2 or worse on histology [Table 14b, Wales 2010-11\*]. In England the figure is 17.4% [Table 18, England 2010-11\*\*]. We use 21% in these calculations, which is an average of the proportions in Wales and England.

Based on earlier assumptions (see [here](#)), the number of moderate and worse was  $3.3\% \times 1.35 \times 54,972 = 2,449$  and of the latter,  $84\% = 2,057$  will be treated. The number of referrals due to a borderline and mild test result is  $30.8\% \times 11.2\% \times 1.1 \times 54,972 = 2,086$ . Of the latter,  $21\% = 438$  will be treated, yielding a total number treated of **2,495**.

\* Cervical Screening Programme – Wales, 2010-11: Report is available on <http://www.screeningservices.org.uk/>

\*\* Cervical Screening Programme – England, 2010-11: Report is available on <http://www.ic.nhs.uk/>



# Number of stage 1A and stage 1B+ cancers in women aged 20-24 with screening from age 20

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- The number of stage 1A cancers in women aged 20-24 with screening from aged 20 is based on the proportion of cancers in women aged under 25 in the cervical screening audit that were stage 1A. In Wales of 40 cancers in women aged under 25, 35 had stage recorded in the audit and 40% of these were stage 1A [Table 7 and Table 7a, Audit Wales 2012<sup>##</sup>]. In England, 48% of cancers in this age-group with stage recorded were stage 1A [Table 6a, Audit England 2011<sup>#</sup>]. The average rate of cervical cancer in women aged 20-24 in Wales between 2004 and 2009 was 4.1 per 100,000 (see table below). This rate is slightly lower than in Scotland (4.4), but considerably higher than in England (3.0). Between 1995 and 2004, the rates per 100,000 in Wales and England were 2.4 and 2.5, respectively. In Wales the rates are particularly high since 2005, whereas in England the rates have never been that high. We use a rate of 4/100,000, which is at the high end of what has been observed in the UK, yielding 20 cancers per 100,000 women over 5 years. Assuming 45% are stage 1A yields **9** stage 1A and **11** stage 1B+ cancers.

Mean rates (per 100,000) of cervical cancer in women aged 20-24

Country	1985-89	1990-94	1995-99	2000-04	2005-09
England	2.2	2.2	2	3	2.9
Scotland	2.6	2.3	2.9	4.6	4.1
Wales	4.4	1.8	2.4	2.3	5.9

<sup>#</sup> NHSCSP audit of invasive cervical cancer, National Report 2007-2010, published July 2011: Report is available on <http://www.cancerscreening.nhs.uk/>

<sup>##</sup> Cervical Screening Wales Audit of Cervical Cancer (CSWACC), National Report 1999-2009, in press



## Number of stage 1A and stage 1B+ cancers in women aged 25-29 with screening from age 20

- The number of stage 1A cancers in women aged 25-29 with screening from aged 20 is based on the proportion of cancers in women aged 25-49 in the cervical screening audit that were stage 1A. In Wales of 32% of cancers in women aged 25-49 with stage recorded were stage 1A [Table 7a, Audit Wales 2012<sup>##</sup>]. The corresponding figure in England was 49% [Table 6a, Audit England 2011<sup>#</sup>]. Taking into account that 40% of cancers in women aged under 25 in Wales were 1A, we use 40% for the proportion in women aged 25-29. The average rate of cervical cancer in women aged 25-29 in Wales between 2000 and 2009 was 15.8 per 100,000. This rate is slightly higher than in Scotland (15.0), but considerably higher than in England (12.4). Between 1995 and 2004, the rates per 100,000 in Wales and England were 11.0 and 9.7, respectively. We use a rate of 15/100,000 yielding 75 cancers per 100,000 women over 5 years. Assuming 40% are stage 1A yields **30** stage 1A and **45** stage 1B+ cancers.

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Mean rates (per 100,000) of cervical cancer in women aged 25-29

Country	1985-89	1990-94	1995-99	2000-04	2005-09
England	11.1	9.1	9.8	9.6	15.2
Scotland	11.4	12.4	13	13.6	16.3
Wales	12.6	9.5	10.3	11.7	19.8

<sup>#</sup> NHCSP audit of invasive cervical cancer, National Report 2007-2010, published July 2011: Report is available on <http://www.cancerscreening.nhs.uk/>

<sup>##</sup> Cervical Screening Wales Audit of Cervical Cancer (CSWACC), National Report 1999-2009, in press



## Number of stage 1A cancers in women aged 20-24 with screening from age 25

- The number of stage 1A cancers in women aged 20-24 with screening from aged 25 is put to **zero**, because we assume that stage 1A cervical cancer is asymptomatic and in the absence of screening all cancers would be diagnosed at stage 1B or worse. In practice there would be a small proportion of stage 1A cancers diagnosed incidentally to symptoms from some other pathology.



# Number of stage 1A cancers in women aged 25-29 with screening from age 25

- The number of stage 1A cancers in women aged 25-29 with screening from age 25 is based on the number of stage 1A cancers in this age group in those screened from age 20 (n=30) plus the number of stage 1A cancers normally diagnosed aged 20-24 that have not yet been diagnosed as stage 1B+ cancer (n=7). These numbers must be modified by the number of the 7 stage 1A cancers that will have progressed to stage 1B+ without being symptomatically detected by age 25 (assumed here to be 2). Thus, we estimate the number of stage 1A cancers to be **35**. We should also take into account that some screen-detected stage 1B+ cancers at age 26 would be screen-detected stage 1A at age 25. The steeply increasing incidence with age means that this beneficial effect of screening from age 25 may counterbalance any progression of cancers that might have been screen-detected at age 23. Nevertheless we conservatively assume there to be no cancers down-staged as a result of screening at age 25 compared to screening at age 23 and again at age 26.

Additionally and possibly more controversially, we assume that none of the CIN3 that might have been treated aged 20-24 would have progressed to cancer by age 25. This is supported by observations regarding the rates of CIN3 registrations compared to the rates of cervical cancer incidence [1] and by the lack of association between screening in women aged 20-24 and subsequent cancer incidence [2].

1. Sasieni P, Castanon A, Parkin DM. How many cervical cancers are prevented by treatment of screen-detected disease in young women? *Int J Cancer*. 2009 Jan 15; **124**(2):461-4
2. Sasieni P, Castanon A, Cuzick J. Effectiveness of cervical screening with age: population based case-control study of prospectively recorded data. *BMJ*. 2009 Jul 28; **339**:b2968. doi: 10.1136/bmj.b2968. Erratum in: *BMJ*. 2009; **339**:b3115



## Number of stage 1B+ cancers in women aged 20-24 with screening from age 25

- The number of stage 1B or worse cancers in women aged 20-24 with screening from age 25 is put to **13** consisting of the 11 such cancers that occur with screening from age 20 and 2 more due to progression of 2 of the 9 asymptomatic stage 1A cancers to symptomatic stage 1B+ cancer by the age of 25. This number is somewhat arbitrary but is supported by the observation that neither the number of all cancers nor the number of stage 1B or worse cancers in women aged 20-24 was seen to be reduced by screening from age 20 [Sasieni et al 2009]. Thus, we allow for a modest (~20%) increase in stage 1B+ cancers in women aged 20-24 and an overall decrease in cervical cancer in this age group in the absence of screening.



## Number of stage 1B+ cancers in women aged 25-29 with screening from age 25

- The number of stage 1B or worse cancers in women aged 25-29 with screening from age 25 is calculated under the assumption that the overall number of cancers aged 20-29 is not affected by screening from age 20 compared to age 25. Thus, the total number of cancers is 95 and with 35 stage 1A cancers there must be 60 stage 1B or worse. Since 13 of these were diagnosed aged 20-24 there must be **47** at age 25-29.



**P-04-640 Bring Down the Age of Smears to 18 - Correspondence from the Petitioner to the Committee, 30.09.15**

My petition which is in the hands of my MP and there are also two more petitions with over 100'000 signatures from other people waiting to go to parliament

[https://www.change.org/p/government-bring-down-the-age-of-smears-to-18?recruiter=258759281&utm\\_source=share\\_petition&utm\\_medium=facebook&utm\\_campaign=share\\_facebook\\_responsive&utm\\_term=mob-xs-guides-no\\_msg](https://www.change.org/p/government-bring-down-the-age-of-smears-to-18?recruiter=258759281&utm_source=share_petition&utm_medium=facebook&utm_campaign=share_facebook_responsive&utm_term=mob-xs-guides-no_msg)

Please could you use Jessica's page for evidence and hears a list of some of the young woman who have passed away from cervical cancer in the last two years that I know of

<https://www.facebook.com/pages/Jess-Bradford's-cervical-cancer-awareness/1497557637123806>

Document is Restricted

## P-04-539 Save Cardiff Coal Exchange

### Petition wording:

This petition seeks a commitment from the Welsh Government to set up a public enquiry into the events surrounding the Coal Exchange and to support public opinion which seeks to protect and conserve the building.

The Coal Exchange is one of Cardiff's most important buildings and one of the finest buildings in Wales. It's where the world's first million pound deal was struck during the city's industrial heyday (equivalent to over £100m today). Yet far from cherishing this building, Cardiff council proposes to demolish the main body of the building, keeping only the facades.

If this happens, then the magnificent interior with its immense historical significance will be lost forever. This grade 2\* listed building deserves better, and the views of the public need to be heard.

The Council have been claiming for the past year that it is on the point of collapse. No works have been done, yet there is no apparent evidence that the building is about to collapse. It is questioned if Cardiff Council were able to use section 78 powers under the building act to progress their plans, and this needs to be investigated openly.

So much of Cardiff Bay's social and built heritage has already been destroyed; it seems inconceivable that more can be cast aside with cynical abandon.

It's unclear why the council refuses to see the value of restoring the Coal Exchange to protect this iconic building for the use and enjoyment of future generations.

The issues are of the highest level of public interest, and it is considered essential that an open public consultation occurs to review matters.

**Petition raised by:** Jon Avent

**Date Petition first considered by Committee:** 11 March 2014

**Number of signatures:** 389 signatures. An associated petition hosted on another website collected 2680 signatures.

Edwina Hart MBE CStJ AC / AM  
Gweinidog yr Economi, Gwyddoniaeth a Thrafnidiaeth  
Minister for Economy, Science and Transport



Llywodraeth Cymru  
Welsh Government

Eich cyf/Your ref P-04-539  
Ein cyf/Our ref

William Powell AM  
Assembly Member for Mid & West Wales  
Chair - petitions committee

committeebusiness@Wales.gsi.gov.uk

14 August 2015

Dear William

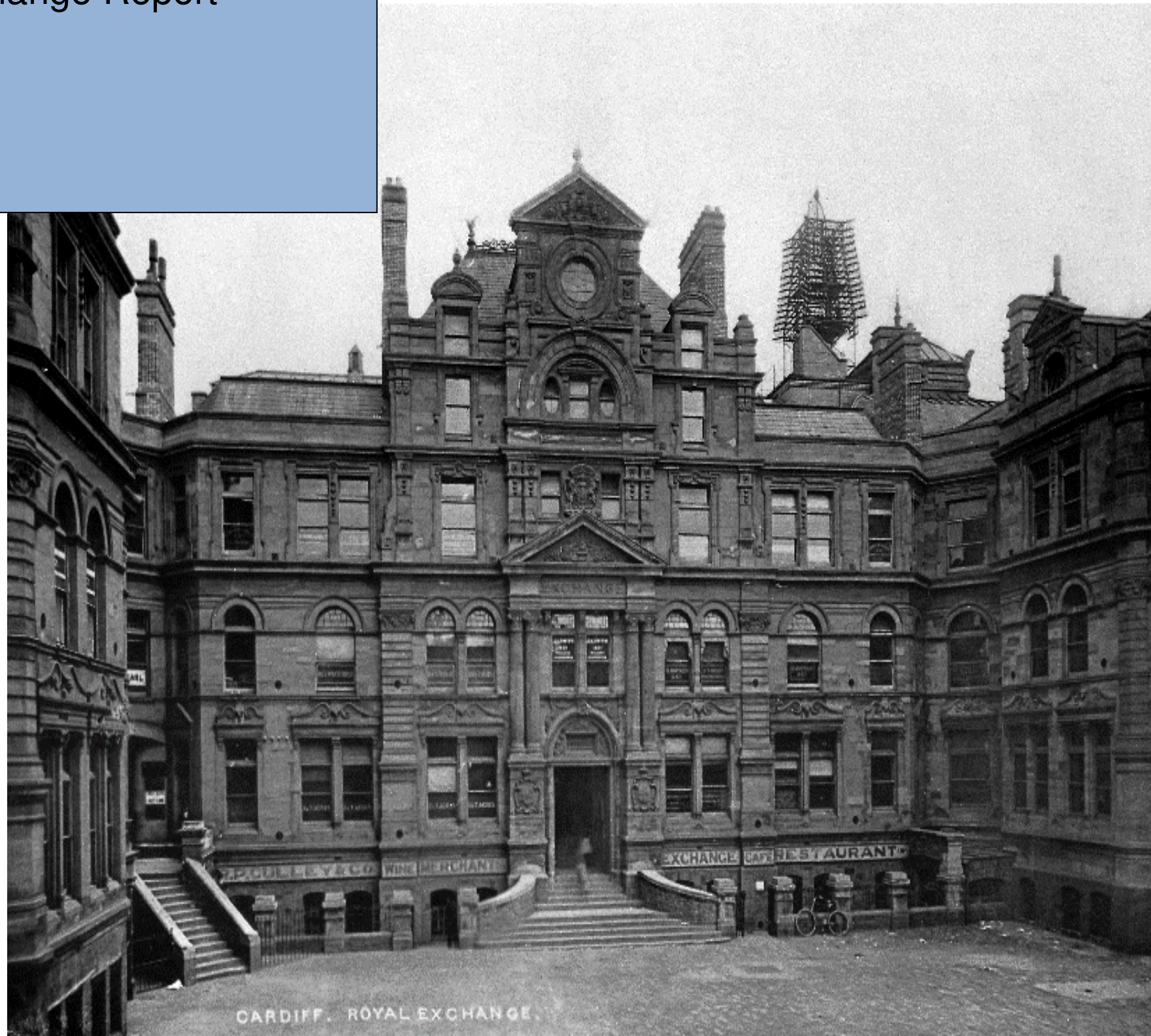
Further to my letter of 30 June regarding the Cardiff Coal Exchange, please find attached as promised a copy of the feasibility study prepared by Capita in association with Economy Science and Transport and CADW officials.

*Edwina Hart*

# CAPITA

## Coal Exchange Report

14 July 2015



## Quality Management

Job No	CS/079052		
Project	The Coal Exchange, Cardiff		
Location			
Title	Report on the condition and potential re-use options for The Coal Exchange		
Document Ref		Issue / Revision	
File reference	F:\CAPITA_SYMONDS\Projects\Commercial\CS 079052 Coal Exchange\Report		
Date			
Prepared by 1	Sarah Parr	Signature (for file)	
Prepared by 2		Signature (for file)	
Prepared by 3		Signature (for file)	
Checked by	Chris Wright	Signature (for file)	
Checked by		Signature (for file)	
Authorised by	Derek Russell	Signature (for file)	

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- Appendix B – Zone Plans
- Appendix C – Areas retaining high levels of original fabric
- Appendix D – Historic Wales Report 140115
- Appendix E – Example building wraps
- Appendix F - Sources of Material

## Revision Status / History

Rev	Date	Issue / Purpose / Comment	Prepared	Checked	Authorised
A	25/06/2015	Amendments following meeting 24/06/2015 – awaiting final comments from CADW	SP	CW	DR
B	14/07/2015	Amendments following CADW recommendations	SP	CW	DR

## 1. Executive Summary & Recommendations

### 1.1 Building Condition

The building is generally dilapidated with some areas dangerous and inaccessible. The building does not meet current regulations for occupation in terms of fire travel distances, disabled access and most statutory compliance regulations. In several areas within the building there is evidence of asbestos containing material, dry rot and rodent infestation.

### 1.2 Building Significance

The Coal Exchange is a listed Grade II\* and is one of the most historically important commercial buildings in Wales, illustrating the region's immense commercial power in the late nineteenth century and early twentieth century. The most significant heritage components are:

- Exchange Hall including foyer, hall and ante rooms including the whole atrium, balcony galleries and the original roof.
- Front and East facades
- South entrance courtyard, though more than partially obliterated by the car park.
- The whole layout of the building with its interconnectivity between trading floor, galleries and offices
- Roof features including cupolas and turrets and general massing.

### 1.3 Approach to Redevelopment

This report represents a pragmatic approach to redevelopment which recognises the need to achieve sustainable commercial use whilst refurbishing and retaining as many of the significant heritage components as possible.

The approach used in this report also recognises the need to provide a variety of room sizes to suit a wide range of potential uses including office/commercial, creative arts/crafts, leisure, cafe/restaurant, exhibitions, concerts and conferences.

### 1.4 Recommendations

It is recommended that a phased approach to the refurbishment of the building is adopted. Initially it is important to fill in knowledge gaps with further and better surveys and investigation work.

- Health and Safety review including risk assessments
- Full building conditional survey including the roof
- Independent structural survey
- Measured to survey to production up to date plans and elevations
- Detailed conservation statement and conservation management plan
- Asbestos survey
- Pre-application discussions with local authority conservation officer and Cadw
- Detailed agreement with Cadw of the scope of the refurbishment
- The above can be undertaken separately. An allowance of circa £200,000 should be allowed for all this work.

Once a full understanding has been achieved of the risks and consequential costs of the various aspects of the building refurbishment, an initial work package to protect and make the building weather resistant and stable should be undertaken. Reconstruction work can then take place in phases and this is summarised below.

Phase	Works	Costs £k	Fees £k	Totals £k	Cumulative Totals £k
1	Investigations and Surveying (7.2)	-	200	200	200
2	First Works (7.3)	3,155	474	3,629	3,829
3	Zone 1 (7.5)	1,978	297	2,275	6,104
4	Zone 2 (7.6)	10,087	1,513	11,600	17,704
5	Entrance Area (7.7)	750	112	862	18,567
6	Delivery / Goods Access (7.8)	400	60	460	19,027
7	Zone 3 (7.6)	9,252	1,378	10,640	29,667
8	Zone 4 (7.6)	7,415	1,113	8,528	38,195
8	Zone 4 demolition Alternative (7.6)	187	280	2,155	

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## 2. Purpose of the Report

2.1 This report has been produced for the sole use of the Welsh Government in order to provide an overview of the condition of The Coal Exchange building and to consider repair and re-development options. These options range from initially making the building safe and watertight through to the refurbishment of the entire building on a zone by zone basis. High level indicative costs for each category of repair and option for refurbishment have been provided.

## 3. Methodology

### 3.0 Introduction

This report is not a condition survey but is a review of the building condition based on site visits, reports provided by other consultants, research and meetings with relevant organisations.

### 3.1 Site Visits

An initial familiarisation visit was carried out on Monday 9<sup>th</sup> March 2015, which involved a walk-around of the building to get a general overview of its condition and layout.

A two day inspection was conducted on Wednesday 18<sup>th</sup> and Thursday 19<sup>th</sup> March 2015 by Sarah Parr (Capita Building Surveyor) and Nick Renwick (Conservation Architectural adviser). Each accessible room was inspected and rated based on the categories in 3.3. Areas that were too dangerous to inspect and also areas where access wasn't gained, have been highlighted on the plans in Appendix A. These areas have been rated as category 4 based on a worst case scenario for the purpose of calculating costs.

A meeting was held on site at The Coal Exchange with RVW Consulting on Wednesday 25<sup>th</sup> March 2015. An external walk-around of the site was conducted together with a discussion of their previous report findings.

It should be noted that no roof inspections were carried out due to unsafe access. Comments on the condition of the roof are based on information from previous reports.

### 3.2 Condition Evaluation

Initially the buildings condition was evaluated on the basis of the following repair categories;

<b>Category 1</b>	Areas currently in use as office accommodation requiring minor repairs / decoration, provision of compliant escape routes, disabled access compliance, upgrading of electrical / heating / toilet facilities.
<b>Category 2</b>	Areas which can be brought back into temporary use with works as Category 1 plus minor repairs to floors, walls, ceilings, windows and doors.
<b>Category 3</b>	Areas which are capable of being repaired economically. Such repairs will include replacement of floor and roof structures, structural repairs to walls and all repairs / decorations associated with category 1 and 2 work.
<b>Category 4</b>	Areas which are not capable of reasonable economic repair because of their extremely poor condition. These areas are currently in a dangerous state and will either need to be demolished or reinstated completely following selective demolition.

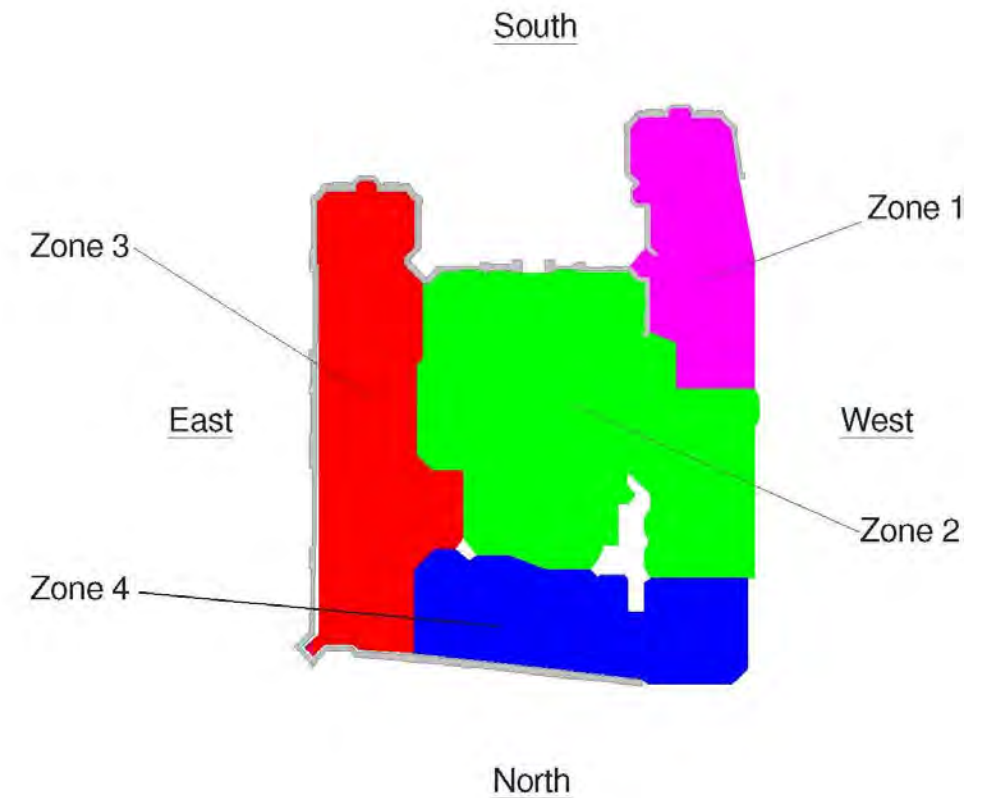
These categories were agreed with Welsh Government, Capita and Nick Renwick Architect (Conservation Architectural Adviser) and drawings showing these categories are provided in **Appendix A**. These drawings also show areas where no access was possible generally due to the dangerous condition of the building.

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## 3.3 Evaluation of Potential Refurbishment Works

Following the evaluation of the buildings condition, the building was split into four zones to evaluate phasing for repairs and refurbishment works.

Zone 1	South West corner extending half the length of the western side. Floors ground, first, second and third / roof space.
Zone 2	Main hall, rooms between the southern elevation and the main hall and some rooms between the western elevation and the main hall. Floors ground, first, second and third / roof space.
Zone 3	South East corner to North East corner including rooms along the eastern elevations extending to the Main Hall. Floors ground, first, second, and third / roof space.
Zone 4	Rooms from the Northern elevation to meet zones 2 and 3. Floors ground, first, second and third / roof space.



Drawings showing these zones are contained in **Appendix B**.

## 3.4 Building Refurbishment Options

In considering how the building would be refurbished the following assumptions were developed and agreed with Cadw.

### 1. Initial work packages (options 1A and 1B)

A basic package of work comprising facade retention including full scaffolding and a full 'top hat' temporary roof would be the first work to be undertaken making the building safe and watertight (option 1A in Section 6.0). This initial work could be augmented with a building wrap which is a material used to cloak the building elevations to provide an external appearance similar to the elevations of the building behind the wrap (option 1B in section 6.0)

### 2. Zone 1 Refurbishment Option 2.

The next work package would be to fully refurbish zone 1 at all floor levels and make it ready for occupation. This would mean that all floors would become structurally sound, all finishes and decoration renewed, wiring and heating replaced, new toilets, lift access made available, fire escape routes put in place, windows repaired / replaced, roof repaired / replaced and external walls fully repaired on completion of this work.

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## 3. Zone 2 Refurbishment Option 3

This refurbishment package has been split into subsets 3A, 3B and 3C. Option 3A provides for a fully refurbished and fit for occupation ground floor with the upper floors structurally sound but otherwise un-refurbished. Option 3B provides refurbished ground and first floors with all floors above structurally sound. Option 3C is the refurbishment of Zone 2 at all floor levels and the roof refurbished.

## 4. Zone 3 Refurbishment Option 4.

This refurbishment package has been split into subsets 4A, 4B and 4C. Option 4A provides for a fully refurbished and fit for occupation ground floor with the upper floors structurally sound but otherwise un-refurbished. Option 4B provides refurbished ground and first floors with all floors above structurally sound. Option 4C is the refurbishment of Zone 2 at all floor levels and the roof refurbished.

## 5. Zone 4 Refurbishment Option 5

This refurbishment package has been split into subsets 5A, 5B and 5C. Option 5A provides for a fully refurbished and fit for occupation ground floor with the upper floors structurally sound but otherwise un-refurbished. Option 5B provides refurbished ground and first floors with all floors above structurally sound. Option 5C is the refurbishment of Zone 2 at all floor levels and the roof refurbished.

## 6. Zone 4 Demolition Option

This option assumes that the external facade is retained and that the area of the building in zone 4 is demolished. This work package also includes providing external wall ends to close the building in order to make it weather tight. The reasons for considering this option are provided in Section 7.



A summary of the refurbishment options is shown in the table below.

Option	Facade Retention	Temp Roof	Building Wrap	Zone 1		Zone 2				Zone 3				Zone 4				Demolition Works
				All Floors	Roof	GF	1st Fl	2nd & 3rd Fls	Roof	GF	1st Fl	2nd & 3rd Fls	Roof	GF	1st Fl	2nd & 3rd Fls	Roof	
1A	✓	✓																
1B	✓	✓	✓															
2	✓	✓	✓	✓	✓													
3A	✓	✓	✓	✓	✓	✓			✓									
3B	✓	✓	✓	✓	✓	✓	✓		✓									
3C	✓	✓	✓	✓	✓	✓	✓	✓	✓									
4A	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓			✓					
4B	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓					
4C	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓					
5A	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓				✓
5B	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓
5C	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
5D	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓					✓

### 3.5 Input from Cadw

Several informal meetings were held within Cadw to discuss progress in the evaluation of the building and to provide input into the Initial Conservation Study found in section 5 of this report.

### 3.6 Initial Conservation Study

Section 5 of this report has been produced by Nick Renwick (Conservation Architectural Adviser) and provides the basis of thinking which informed the definitions of the condition evaluation categories, the subsequent refurbishment zones and the options considered in section 6 of this report.

## 4. Overview of Condition

### 4.1 Introduction

A visual high level inspection was carried out on Wednesday 18<sup>th</sup> and Thursday 19<sup>th</sup> March 2015, where categories were given to each accessible room within the building.

It is difficult to consider each category as separate entities on a floor by floor basis. For example, areas of category 1 and 2 on the ground floor may have areas above on the first, second and third floors that are category 3 or 4. The roof is likely to be defective above these areas also. It was agreed that the best approach to such variations in condition is to consider the building on the basis of zones. Four zones were agreed and each contains a variety of differing categories of repair.

A desk top study of previous reports on the building has been carried out and this information has been used in conjunction with our own findings on site from the visual inspection.

### 4.2 Health and Safety

The health implications of the building must also be considered. There were areas of asbestos which have been labelled as asbestos containing materials. A full refurbishment and demolition survey would need to be conducted prior to any refurbishment works.

Precautions will also need to be taken against further health risks posed within the building. It was noted during our visits that there is an extensive amount of pigeon carcasses and faeces and precaution would need to be taken against Psittacosis. There were visible fungi fruiting bodies and mycelium in some accessible areas, which will release spores into the atmosphere. It is also anticipated that there is an extensive rodent infestation and precautions would need to be taken against Leptospirosis.

### 4.3 Statutory Compliance

A DDA assessment and fire risk assessment have not been carried out. However, it is apparent from the visual inspection that in it's current form the building is not compliant with current regulations. Furthermore, the mechanical and electrical installations would also require replacement / upgrading to meet current regulations.

The implications of this are that lift access will need to be provided, new heating and toilet facilities installed, additional fire escape stairs provided together with improved fire escape routes and a complete rewiring needs to be undertaken.

### 4.4 General Overview

- There is extensive water penetration as a result of a combination of factors; leaking roofs, blocked and leaking rainwater goods, cracks and vegetative growth in the walls to list a few factors.

- In many areas there has been total and partial floor collapse and there is evidence of other areas of floors beginning to lose their structural integrity.
- The collapsing floors have caused damage to the walls by dislodging the masonry and jeopardised the stability of the walls / facades.
- There are extensive areas of rotten floor and roof timbers and this is especially evident in areas where the timbers are in contact with the external walls.
- The roof areas have not collapsed but there is a risk that this could occur. Many of the roof timbers are rotten and are no longer performing their structural role. Snow and extreme wind loading will have an impact on the stability of the roofs.
- The north-west and south-east wing are in danger of collapse.
- Each elevation has cracked and loose masonry.
- Many of the ceilings have coal ash pugging to act as an acoustic barrier. When this material becomes wet it changes to a concrete like substance and thus imposes additional weight onto the timber. This can contribute to the collapsing of ceilings when combined with the continued water ingress causing rotten timber.

### 4.5 Roofs



The building has a complex roof formation, made up of pitched roofs with slate and glazed areas and of flat roofs. We were unable to inspect the roof during our visual inspection due to unsafe access. Where we have made comment on the condition of the roof, we have used information from previous reports.

#### Slate covered roofs

- Nail fixings have corroded in many locations.
- Weathered and loose pointing to ridge and hip tiles evident on all roofs.
- Cracked and loose ridge and hip tiles.
- Delaminating slates.
- Lack of felt below the slates in many areas.
- Insufficient sized tiling fillets at eaves and valley gutter locations.

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## Glazed roofs

- Poor lead detailing between glazed panels corresponding with areas of staining and leaks internally.
- Evidence of numerous patch repairs, not all successful.

## Flat roofs

- Flat roof on west elevation constructed in bitumen felt over a timber decking. In poor condition with split and blistered areas, allowing continued water penetration.

## Parapet gutters and rainwater goods

- Lead lined parapet gutters in a poor condition, with areas that have been patch repaired with bitumen felt and bitumen coatings.
- Rainwater outlets and downpipes are blocked causing a back up of water in the gutters and a continued overflow of water down the face of the building in the areas around the blocked and leaking gutters.
- Water staining internally below the outlets and gutters indicate continued leakage.

## 4.6 Chimneys

- Chimney stacks are all in a poor state of repair.
- Excessive weathering of the mortar joints to the stacks, resulting in loose stones and bricks.
- Many stacks have extensive vegetative growth in the recessed joints.

## 4.7 External fire escapes

- Two external fire escapes in the light well elevations, both from the North wing third floor.
- One fire escape of steel construction and in a poor state of repair.
- One fire escape of timber construction and in a state of collapse.

## 4.8 North West Wing



North Elevation

## West Elevation

Access to this area was on the ground floor as all other floors were unsafe to enter. Combining our findings and previous reports, we can provide the following overview of the area.

- There has been a total collapse of floors at first and second floor level, which has caused damage to the walls in the process and resulted in a lack of restraint of the walls.
- Floor areas around the north-west wing have been propped in instances of partial floor collapse. These floors are still suffering from continued damage from water penetration.
- The facade is showing signs of settlement.
- Many of the accessible roof timbers in this area are rotten and have lost their structural integrity. Rotten timber lintels are no longer providing support to the roof trusses.
- Areas of stress to the window jambs have caused the facade stone to split, allowing water penetration and cracks to progress in size due to the free-thaw action.
- Action is required to protect this area from collapse.

## 4.9 South East Wing



This area is in a critical condition and access was extremely limited due to the unsafe condition of the area. With our own findings in combination with previous reports we can provide the following overview below.

- Floors at all levels have collapsed, resulting in removal of lateral restraint over the full height of the wing.
- The structural loads have been transferred to the outer decorative leaf of stone, causing the window heads and jambs to split.
- The west elevation of the south-east wing is exhibiting signs of immediate instability, as there is no structure tying the masonry back to the main structure.
- There is damage to the stone facade from falling masonry and evidence of masonry on the ground during our inspection.

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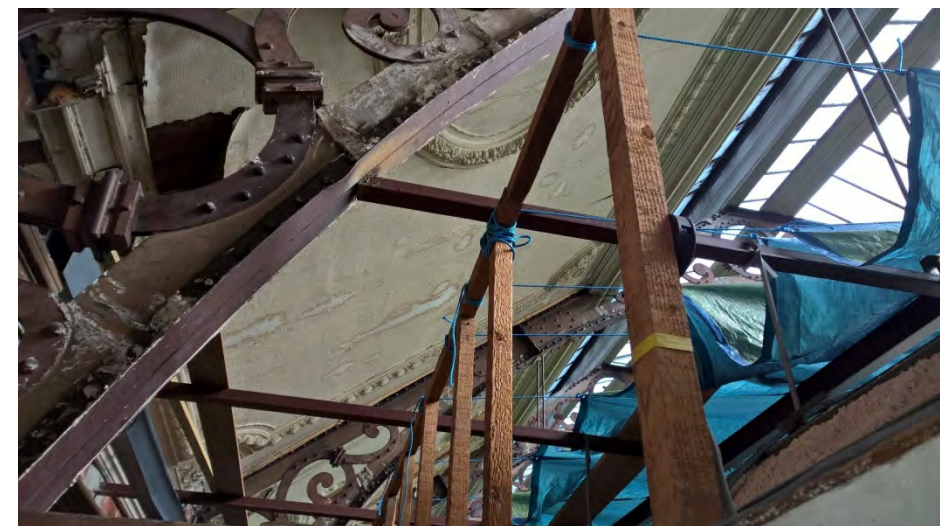
- Action is required to protect this area from collapse.

## 4.10 Main Hall



The main hall on the ground and first floor is in a reasonable condition in comparison to other areas of the building, with localised areas of repair required. However, the condition deteriorates as the building moves up to the second floor and the glazed roof area. This deterioration will eventually feed down through to the currently less impacted areas, so a/an holistic approach needs to be taken / adopted.

The ante rooms are also in a reasonable condition on the ground floor, however the condition deteriorates further up the building. There has been a total collapse of floors in areas on the second floor and evidence of continued water ingress. Again, an approach to address the roof and damaged areas above the ante rooms will be required to prevent the deterioration migrating down to the ground floor.



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## 5. Initial Conservation Study

### 5.1 Introduction

The Coal Exchange is the centre piece of Mount Stuart Square built largely in limestone in the French Renaissance style. The scale and rich architectural detail serve to illustrate the region's immense commercial power in the late 19<sup>th</sup> century and it has a strong presence within the streetscape.

This building dominates the square by its design even though some of the buildings around are larger. This is due to the intricate detail and architectural massing of the elevations, the former breaking down the latter, which in turn turns breaks down the monumental scale.

The whole building is listed Grade II\* as one of the most historically important commercial buildings in Wales, illustrating (the) region's immense commercial power in the late C19 and early C20. *Historic Wales Report 14015*. See Appendix D.

### 5.2 Understanding the Site

#### HISTORICAL BACKGROUND

Cardiff was for over 50 years the largest coal port in the world with the mineral brought down from the coal bearing valleys to the north first by canal boat and after the 1840s by rail way and then shipped out of Cardiff. Trade such as this needs a market that can adapt immediately to changes in supply and demand and initially the coal owners and ship owners met in the local public houses and offices.

However this could not last as trade increased exponentially with more and more coal and ship owners, agents, brokers and merchants moved to Cardiff from areas like Newcastle, Liverpool, London and the West Country to service the industry and make profits out of the Black Gold. Therefore a purpose built building was deemed necessary similar to other national trading market buildings such as the Baltic Exchange in London or the Cotton Exchange in Liverpool.

The site chosen was the garden area in the centre of Mount Stuart Square. This had originally been built as a residential square on the lines of a London Square populated by the middle echelons of the docks merchants, however the houses had gradually been taken over by offices as the area became Cardiff's commercial centre.

The building was constructed in phases between 1883 and 1897, these were almost continuous as economic pressures kept the building work progressing. The exchange floor was both first and last as it was redesigned in 1911. The changes appear to have been cosmetic with the trading booths removed and more detail applied to the balconies.

Edwin Seward was the architect and Edward Turner the building contractor. Financing was initially by subscription raised through the business community but as the first phases came into operation the management company raised finance through profits and rents.

Edward Turner was the 'go to' builder for the Cardiff establishment. As was common in this period the contract would have been similar to a Design and Build procurement scenario with the contractor given scheme design drawings and expected to provide his own working details and build within a contract sum. This probably accounts for the bland elevation and absence of detailing to the North / West elevations.

The economic zenith of the Exchange and indeed the port of Cardiff, was immediately before the First World war and from then it went into a gradual decline culminating in its closure as a trading floor in 1961. The stock exchange carried on until the late 1960s using its own trading premises on the first floor.

The building has had various uses since then, as a concert hall or exhibition space and twice it has been proposed as the site of the Welsh Parliament, but no use has stuck and the building as a whole has continued to decline.

The wings of the building including the offices to the rear continued to be used as offices, many of them populated by the residuary shipping firms that carried on in ever reducing circumstances throughout the century. The North East corner housed Barclays Bank until 15 years ago and a Housing Association occupied the first floor of the North section until 20 years ago. New 'up to date' entrances were constructed for both. Because of the poor materials used both have deteriorated quicker than the building itself.

The South East wing experienced a bad fire in the late 1980s, which damaged irretrievably the interior structure, however the exterior has remained intact.

Media companies set up home in the South West and West wings in the 1990s and combined with the concerts being held on the exchange floor, the building seemed to take on a new existence. However Cardiff Bay Development Corporation purchased the entire building in 1989 and though their first aim was 'To promote development and provide a superb environment in which people will want to live, work and play' they failed to get to understand the building and the renaissance stalled and withered.

#### Components

The building to the front was constructed around a grand forecourt enclosed by two wings with steps leading up to the main entrance to the Exchange floor, the remainder of the building was offices serving the Exchange. The plan form is rather eccentric firstly because of the irregular shape of the original garden and secondly to provide each office with windows. As a result there are internally a number of internal courtyards and light

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wells and lean to roofs, creating what would now be termed an overdevelopment of difficult to maintain buildings.

The original design drawings include additional entrances on the West elevation and at the North West Corner. However no evidence of these can be seen in the building fabric and so it is assumed that they were never constructed.

The main part of the building was constructed in pale cream limestone (Corsham Stone) on a sneaked grey stone plinth. This applies to all exterior elevations apart from the North and majority of West in these areas a yellow brick has been used, which gives it a more utilitarian appearance.

The design is described in the listing as derived from French Renaissance. The full text can be seen in the appendix .It is three storeys high plus accommodation in roof pavilions and a basement throughout.

The internal wings behind the exchange floor are constructed in local Radyr stone and are plain and lacking in detail. There are indications that the original design was more elaborate as the stone window sills have stone stooling which should have supported stone surrounds. The internal elevations to the north wings are faced in white ceramic brickwork, which though give a lavatorial feel serve to enhance reflectance to light the internal courtyards.

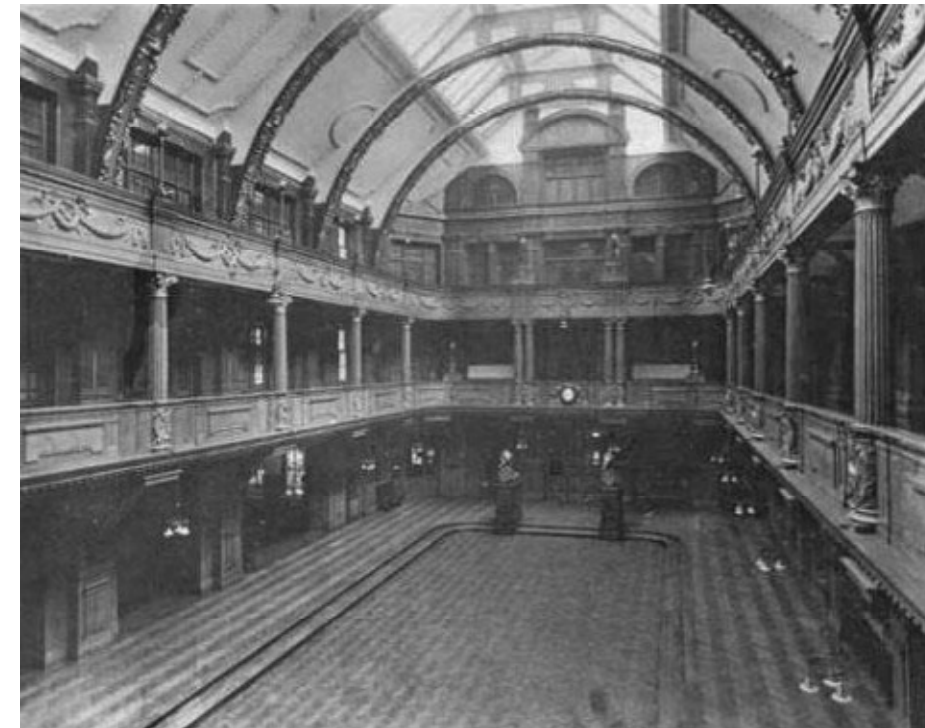
The physical centre and heart of the building was and still is the Exchange floor where it is purported the first £1 million deal was done or cheque written; the story varies. This formally called the Coal and Shipping Exchange was reached by an axis of corridors going North, West and East each leading to separate entrances onto the square as well as the main entrance to the south.

The floor was an atrium with offices on the two upper levels leading off balconies overlooking the floor. The dealing floor itself went through a number of layout changes with dealing booths replaced over the years by an open cry system. The Listing describes the Exchange floor as' comprises an oak panelled room 15mx29.5m with 2 tiers of balconies above the trading floor. It has a glazed roof at the full 17.5m height of the Hall, supported on iron trusses. The ante-rooms (to the floor) were also finished in panelling with stained glass windows and fittings in the architectural style of the day.

From 1961 to the present time some unsympathetic alterations have been carried out, including the insertion of a false acoustic ceiling above the exchange floor in the 1970s, so hiding the upper level gallery and the roof trusses. Also the ruination of the entrance courtyard with an underground car park.



AERIAL PHOTOGRAPH FROM EAST



THE EXCHANGE FLOOR IN 1912

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THE EXCHANGE FLOOR IN 2014

Changes since the start of the Twentieth Century were negligible, the most significant being the demolition of the railway offices constructed in the front forecourt.

In order to promote the late 1960s uses new entrances were constructed around the main forecourt and North entrance and escape stairs inserted behind. These using concrete and aluminium would have appeared up to date interventions at the time but now look tired and out of place.

In its pomp the Exchange Building served as a catalyst to redevelop the whole area around. The houses around, all originally designed for domestic use, became offices and many were demolished and multi floored purpose built offices erected in their stead. This redevelopment spread out to the streets around James St, Bute St and West Bute Street.

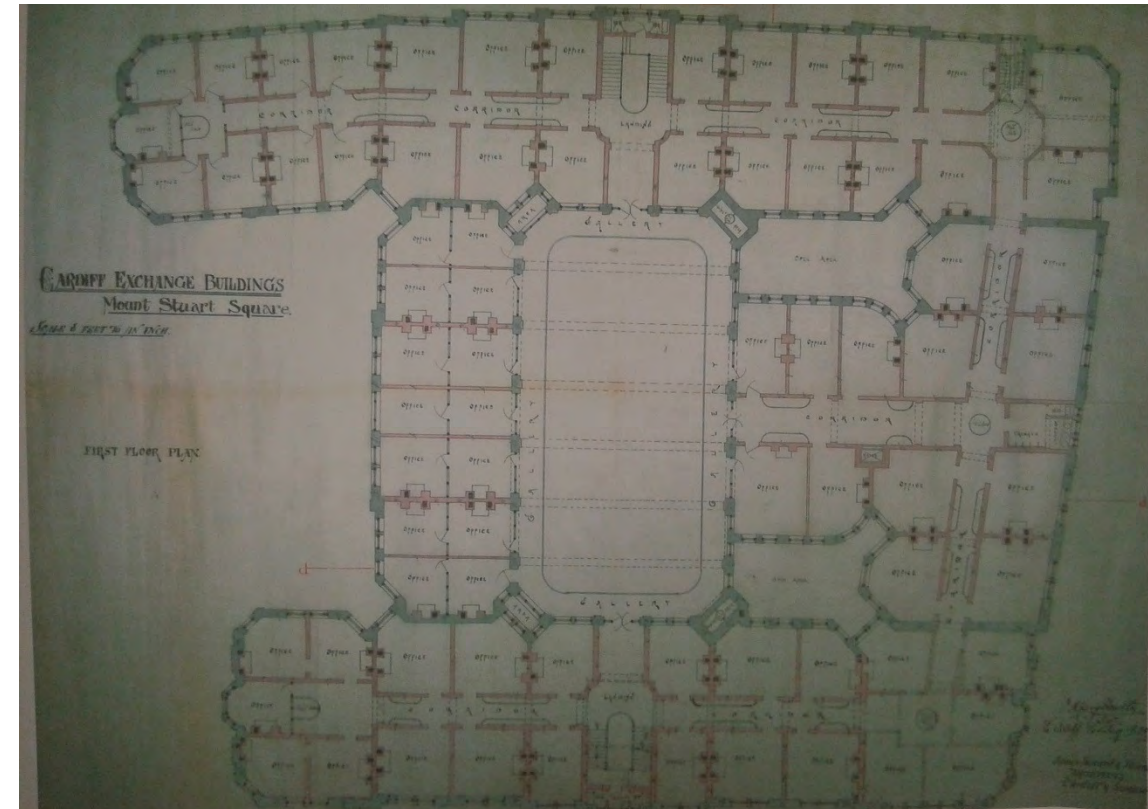
## 5.3 Assessment of Significance

### SIGNIFICANCE

The building contains one of the only extant dealing floors left in Great Britain, others like the Baltic Exchange in London have been demolished, whilst the Royal Exchange in Manchester became a theatre and the Joint Stock Building in Birmingham is a Pub/Restaurant. It is a testament to how business was conducted in the 19 and early 20<sup>th</sup> century. The building was dynamic in itself creating and promoting business throughout the world whilst at the same time providing purpose built offices for the firms

doing business there. It even provided its own leisure facilities with a Members only club off the exchange floor and restaurants in the basement.

Architecturally, the Exchange floor and south and east entrances are of particular significance in design terms, but taken as a whole the building is a footprint of a Victorian business centre and should be treated as an entity. It was, using words from a modern advertisement for office space, Ready-to-go workspaces with the widest possible range of complementary support services available on demand.



Floor Layout

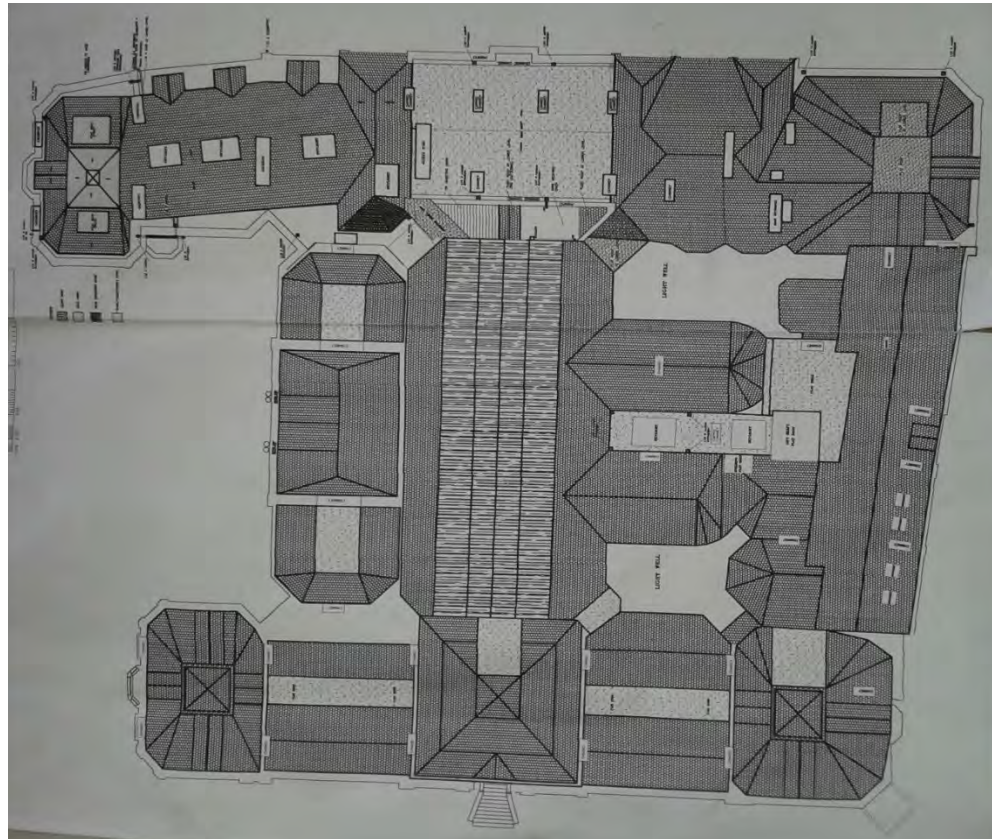
### AREAS OF ORIGINAL FABRIC AND CHARACTER

It is always invidious with a complex building to make judgements without a detailed assessment but the initial visual inspection has indicated that the following areas retain particularly high levels of original fabric and historic character:

Exchange Hall including foyer, hall and ante rooms including the whole atrium, balcony galleries and the original roof.

- All facades.
- South entrance courtyard, though more than partially obliterated by the car park.
- Roof features including cupolas and turrets and general massing.

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ROOFSCAPE

## LEGIBILITY OF ARCHITECTURE

The exchange floor is basically unaltered on the ground and first floor. The original features and fittings have mercifully been kept. It is at second floor level that interventions have obscured the architectural narrative with the insertion of the suspended ceiling which truncates the atrium.

The ceiling even though attempts were made to soften its design by curving the perimeter, remains a problem. Not only does it destroy the elegance of the atrium, it also cuts off the second floor balcony and gallery, the last by cutting away the ranks of offices behind and their interconnectivity with the exchange floor losing the ethos of the original design.

The building as a whole was originally designed on a cruciform pattern with the exchange floor as its crucible served by entrances at each point of the compass with galleries leading from each entrance to the exchange floor. Though the galleries have been obstructed and the west entrance lost the pattern is still there and can easily be restored.

The offices are all of a rigid cellular layout each with its chimney flue if not fireplace. In some areas the timber screen that separated off the ante room from the inner sanctum remain. All with the exception of those overlooking the balconies have natural light. This

is because of the layout of the whole building with light wells and inner courtyards. Unlike many other buildings of this period these have not been filled in or built over.

## DEFICITS

Apart from its general condition, access for the disabled is the main deficit of the layout. With all main areas at upper ground level and above there is little option for creating level accesses apart from the main entrance area, however this is bound up with the whole layout of the 1970s car park. Interestingly a lift was originally constructed to serve all floors. It was in the well to the south-east of the exchange floor and the mechanism is still in the motor house on the roof. The floors were originally constructed with sand or sea shell pugging and where the floors are stable these remain so creating both fire resistance and acoustic insulation.

There are a number of fire escape structures but many of these are unusable firstly because of their structural disrepair and secondly because the ultimate means of escape are blocked. However it should be noted that this is not the case the currently occupied areas of the building.

As previously mentioned the offices are all cellular and divided up by structural walls many containing chimneys so opportunities for open plan arrangements, if proposed are minimal. However this would serve to promote the concept of multi uses for the building, rather than single uses

The 1970s car park cannot economically be restored to effective use. The ramp is too steep, car parking spaces minimal and access poor.

A significant number of basement windows and doors have been lost as the pavement has encroached making the rooms difficult to use. Of the basement itself the 1970s Welsh Assembly pre-contract work has made general circulation impossible. A complete redevelopment of the basement could provide new opportunities such as the creation of new car parking areas. However this would have to be the subject of a detailed study.

## 5.4 Issues & Vulnerabilities

### OBJECTIVES

The building lies in limbo at the moment with the exception of part of the south west wing it is effectively empty and very vulnerable to continual deterioration. There is a dedicated team titled Save the Coal Exchange Ltd that is working to draw attention to the building and its predicament and also provide facilities management for the lettable areas. However it needs a long term purpose to be identified around which all the energies of the business and local community as well as Local and national authorities can coalesce.

Over at least the last 25 years various uses have been put forward. Ignoring the two schemes for a Welsh Assembly, plans have been prepared for practically all use classes

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under the Planning Act. None have stuck. What is needed is one that provides and promotes the future of the Exchange Floor, its entrance and atrium, not as an adjunct but as the heart of the building.

## COMMUNITY EXPECTATION

There were always two communities in Butetown the business and the civil; historically the two did not mix. Therefore the residential community had no expectation of the Exchange apart from a 9-5 office for the business community. Further developments to the east around Mermaid Quay and the Roath Basin waterfront have left Mount Stuart Sq behind as an island divorced from the new areas of affluence.

Since the 1980s when the Cardiff Bay Development Corporation (CBDC) was conceived the lines have become much more blurred between the two with residential sitting cheek by jowell with commercial. Additionally the residential developments have been a mix of so called luxury apartments and affordable and rented housing resulting in a greater mix around Mount Stuart Square, which can only add to the cohesiveness of the community.

Therefore any new use for the Coal Exchange building must acknowledge this and produce a use that all the community can take ownership of.

Mount Stuart Square was like a business village with everyone knowing one another as they were nearly all involved in the same trade. Over the years this has been lost, but because of the physical proximity of all the buildings this attribute has never quite died and could easily be completely resurrected if the Coal Exchange were brought back to life to the advantage of all communities.

## 5.5 Conservation Policy & Principals

### PHILOSOPHY

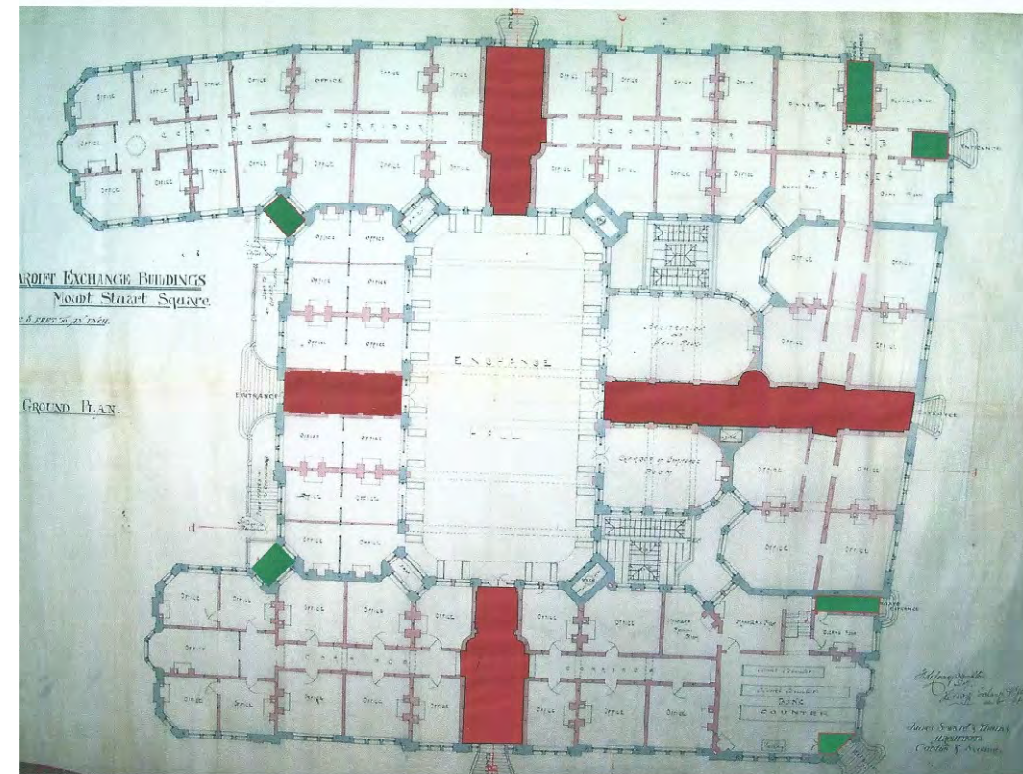
The philosophy proposed is that the original character of the site should be retained and not lost under a welter of contemporary alterations influenced by the prevailing fashions of today.

Established principles of 'conserving as found' will be applied to the building and interventions will only be proposed where significant elements have been modified or lost as in the case of the trading floor roof. However a pragmatic approach is required due to the destruction of finishes due to neglect, fire damage and refurbish works of recent years. Therefore areas exhibiting original features and finishes will be conserved whilst all other areas will be refurbished using modern materials/techniques to resemble the original appearance of rooms.

## VISION

The proposal is that the whole building be altered and refurbished to return it to the uses envisaged by its original architect. That is a self-contained centre with offices, restaurants, leisure facilities and conference facilities. Some areas may also be suitable for exhibitions, craft and arts uses.

This will be done without any major alterations to the building structure, only refurbishment of what is still there and using the geography of the building with its central wings enveloped by its perimeter façade. The only changes proposed will consist of opening up all the original entrances even if they were never actually constructed, so that the building can be accessed from all angles. This will mean that the central passage way leading from each door will lead to the central galleries themselves leading to the exchange floor.



PLAN. Floor layout showing original principal entrances RED & secondary GREEN

The central passage way going north from the exchange floor will become an arcade with offices and shops leading off it similar to those in Cardiff city centre. The spurs leading off it will allow the most flexible use of the building as each will have their own entrances. So linking the building organically with the whole of the square.

The building layout of rooms will be developed to provide a variety of differing room sizes. The majority of the existing rooms will be left as constructed. Where walls and

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building structure are missing, there is an opportunity to provide larger rooms for craft and leisure uses.

The trading floor will remain as it is, a venue for exhibitions, concerts and conferences similar to that of the Oval basin in front of the Millennium Centre but with the advantage of being undercover and properly serviced and secure also in the most opulent restored Edwardian surroundings.

The building should be conserved and repaired as it stands with the need for modern services balanced with the necessity to retain original intent and authenticity. Therefore the original layout will be retained.

Previous studies have advocated demolition and rebuilding of the North West corner of the building. It is accepted that the external finishes of this section are not of the same architectural quality as those on the south and east fronts, however they are not of substandard materials and the settlement of this section is historic and has caused no critical damage. Therefore the section should be kept as is.

The 1970s car park in the main forecourt to the building was originally designed in concrete in the brutalist style of the period. In the late 1980s attempts were made to soften it outline by building of a false 'georgian' balustrade around the roof in cast concrete. Disregarding at this stage the aesthetic imperfections, the whole structure compromises all opportunities for both returning the forecourt to its original state and also creating ramps and steps that are DDA compliant.

## South Elevation



The Front forecourt in 2005



Forecourt in 1910s

## 5.6 Implementation & Review

### PROGRAMME & STATUTORY CONSENTS

It is recommended that early pre-application discussions are held with the appropriate Planning Authority prior to any design work being considered.

Before any physical work can commence Listed Building Consent will be required for any alterations. Listed below are examples of alterations that are foreseen and others may be found after a Full Conservation Plan has been completed.

1. Recreation of external entrances and creation of ramps.
2. Clearing away of 1970s forecourt and rebuilding of original forecourt to main entrance.
3. Removal of suspended ceiling above 2<sup>nd</sup> floor to trading floor and reopening of gallery and rebuilding of original lantern.
4. Opening up of central corridors to form arcades and rebuilding of lost staircases and construction of lifts.
5. Rebuilding of damaged floors particularly that to the South East corner wing.
6. Repairing of all external façades including stone details. .
7. Reroofing of whole building.

## 5.7 Next Actions

- Full Conservation Plan
- Pre-application discussions with the local authority conservation officer and Cadw

## 6. Cost and Area Appraisal

### 6.1 Cost Methodology

An appraisal was made of the condition of the building by allocating four categories of work to each floor.

Broadly these categories were:

Category 1	Currently in use and requiring relatively minor works
Category 2	Can be brought into use after relatively minor refurbishment works.
Category 3	Repair works required.
Category 4	Major repairs to structure and comprehensive refurbishment works required

### 6.2 Cost specification of categories used for costs

The detailed specification for each category of work for costing purposes is as follows:

#### Category 1- Work Specification

We have used costs per m2 for the following items

- Floor finishes (cleaning / new carpets where damaged (limited area))
- Wall finishes (painting / patch repairs)
- Ceiling finishes (painting / patch repairs)
- Doors and wood work repairs and decoration
- Window repairs and decoration
- M&E alterations

Also included are allowances for:

- DDA compliance
- Roof repairs
- Other compliance requirements

#### Category 2 – Work Specification

We have used costs per m2 for the following items

- Floor finishes (new)
- Wall finishes (painting / patch repairs to a greater area)
- Ceiling finishes (painting / patch repairs to a greater area)
- Doors and wood work repairs and decoration (allowance for more repairs than cat 1)
- Window repairs and decoration
- M&E alterations (A higher allowance made to cover new fittings etc)

Also included are allowances for:

- DDA compliance
- Roof repairs
- Other compliance requirements

#### Category 3 – Work Specification

We have used costs per m2 for the following items

- Floor finishes & structure
- Wall finishes & structure
- Ceiling finishes & structure
- New Doors and wood work inc decoration
- New Windows and decoration
- New M&E systems throughout

Also included are allowances for:

- DDA compliance
- Roof repairs
- Other compliance requirements

## Category 4 – Works Specification

We have used costs per m2 for the following items

- Floor finishes & structure (all)
- Wall finishes & structure (all)
- Ceiling finishes & structure (all)
- New Doors and wood work inc decoration (all)
- New Windows and decoration (all)
- New M&E systems throughout (all)

Also included are allowances for:

- DDA compliance
- Roof repairs
- Other compliance requirements

### 6.3 Basis of Costs

- Costs provided are at 2Q2015 prices
- All information contained in Appendix F (sources of material)
- Costs based on a reasonable specification for bringing the building back into use.

### Exclusions

- Abnormal site conditions unless specifically identified
- Works undertaken beyond the boundary of the site (eg local infrastructure works)
- Acquisition costs
- Specialist Equipment
- Costs to conform with conservation specification
- Furniture, fittings and equipment for users fit outs and for general common space

### 6.4 Cost Uplift for conservation works

Until a more detailed study has been completed, it is not possible to assess areas which will require a higher standard of repair. The probable costs for such repairs are not included in these estimates and we consider that a further 30-40% cost uplift may be needed to undertake such works.

### 6.5 Cost Options

Section 3.3 of this report sets out the refurbishment zones for the building and section 3.4 describes the building refurbishment options.

## Facade retention, temporary roof and building wrap

All options include for facade retention work to prop/support structurally unsound walls / floors and a temporary 'top hat' roof. A facade 'wrap' which pictorially shows the elevations of the building and which is attached to external scaffolding has also been included in the costs for all options except option 1B.

## Basement

Costs have been included for making the basement structurally sound, clearing away rubbish, work to walls, structure of the ground floor above and making good of the basement floor. Costs have not been allowed for making the basement usable for car parking, storage or any other use.

## Front Forecourt

Costs for removing the 1970's front forecourt and entrance to the car park are provided separately.

## Deliveries Entrance

The cost to provide a new entrance for deliveries, an access corridor into the hall area and a goods lift are provided separately.

## Cost Options

Cost options are summarised on the proceeding page.

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Examples of Building WRAPS



Examples of temporary roofs or 'top hats'

Option	Facade Retention	Temp Roof	Building Wrap	Zone 1		Zone 2				Zone 3				Zone 4				Demolition Works	Individual Costs £K	Cummulative Costs £K
				All Floors	Roof	GF	1st Fl	2nd & 3rd Fls	Roof	GF	1st Fl	2nd & 3rd Fls	Roof	GF	1st Fl	2nd & 3rd Fls	Roof			
1A	✓	✓																3,030		
1B	✓	✓	✓															125	3,155	
2	✓	✓	✓	✓	✓													1,978	5,133	
3A	✓	✓	✓	✓	✓	✓			✓									8,429	13,562	
3B	✓	✓	✓	✓	✓	✓	✓		✓									452	14,014	
3C	✓	✓	✓	✓	✓	✓	✓	✓	✓									1,206	15,220	
4A	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓			✓					6,731	21,951	
4B	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓					1,215	23,166	
4C	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓					1,306	24,472	
5A	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓			✓	5,981	30,453	
5B	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	474	30,927	
5C	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	960	31,887	
5D	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓				✓		25,716	

New entrance: demolition of existing entrance and bunker, high quality plaza capable of providing an external seating area, allowance £750,000.

Goods Delivery: entrance, access corridor to hall and goods lift, allowance £400,000

## Cost Breakdown by Zone

	SQM	SQFT	ROOMS	COST £	COST/SQM	COST/SQFT	COST/ROOM	Comments
<b>Works to externals</b>				3,155,000				<i>Required works to facade and temporary works to roof</i>
<b>Zone 1</b>								
GF & Roof	381	4,101	11	1,233,951	3,239	301	112,177	<i>Includes roof and structural works to upper floors</i>
FF	371	3,993	9	348,283	939	87	38,698	
SF/TF	422	4,542	13	396,227	825	87	30,479	
<b>Zone 2</b>								
GF & Roof	1,150	12,379	13	8,429,216	7,330	681	648,401	<i>Includes roof and structural works to upper floors</i>
FF	782	8,417	23	452,308	578	54	19,666	<i>mostly a change from cat 1 to cat 2, hence low cost</i>
SF/TF	998	10,742	25	1,205,222	1,208	112	48,209	
<b>Zone 3</b>								
GF & Roof	744	8,008	11	6,731,117	9,047	841	611,920	<i>Includes roof and structural works to upper floors</i>
FF	684	7,363	20	1,214,935	1,776	165	60,747	
SF/TF	1,037	11,162	25	1,305,583	1,259	117	52,223	
<b>Zone 4</b>								
GF & Roof	508	5,468	11	5,980,286	11,772	1,094	543,662	<i>Includes roof and structural works to upper floors</i>
FF	522	5,619	12	474,643	909	84	39,554	
SF/TF	831	8,945	18	959,265	1,154	107	53,293	
<b>Totals</b>	<b>8,430</b>	<b>90,741</b>	<b>191</b>	<b>31,886,036</b>	<b>3,782</b>	<b>351</b>	<b>166,943</b>	

# Note

All Ground floor costs include works to roof and structural work to upper floors to ensure the ground floor can be used safely

All costs are to bring the building into use, **NO ALLOWANCE FOR REPAIRS TO A HIGHER STANDARD HAVE BEEN MADE.**

## 7. Strategies

### 7.1 Report Limitations

In considering the potential strategies for this project it is important to understand the limitations of this report.

- A large proportion of the building could not be reviewed because it was considered to be too dangerous to enter or was locked off for health and safety reasons.
- This is not a building condition survey but a review of the buildings overall status of decay
- A structural survey has not taken place and comments on the structure are based on previous reports undertaken by others
- The extent of areas containing asbestos is not established
- This report includes an Initial Conservation Study. A full Conservation Study is required to achieve full agreement with Cadw for the scale and content of the refurbishment works.

### 7.2 Initial Actions

The next actions should be to fill in knowledge gaps in order for the project to proceed to a strategy.

- Health and Safety review including risk assessments
- Full building conditional survey including the roof
- Independent structural survey
- Measured to survey to production up to date plans and elevations
- Full Conservation Study
- Asbestos survey
- Detailed agreement with Cadw of the scope of the refurbishment
- Pre-application discussions with the local authority conservation officer and Cadw
- The above can be undertaken separately. An allowance of circa £200,000 should be allowed for all this work.

### 7.3 First Works

The first works to be undertaken should be to make the building safe and watertight. We have assumed that this would be for the whole building, even if it was later decided that building renovation works would take place on a zone by zone basis.

- Work to stabilise and make good external walls
- Temporary roof to the entire building
- Work to basement
- Wrap to the scaffolding surrounding the building

- Cost £3,155,000
- Fees @ 15% £474,000

### 7.4 Uses Strategy

In considering a sequence for the refurbishment works we assumed the following:

- There is a need to show early income and commitment to the overall refurbishment of The Coal Exchange.
- Wherever possible the areas of heritage significance should be refurbished first to stop further decline.
- A variety of room sizes should be achieved in order to support the widest uses of the building
- Room layouts would remain as the original design in Category 1 and 2 areas only. Room sizes/shapes in category 3 and 4 areas would be flexible to suit need uses. These rooms would generally be large and be capable of temporary sub division.
- It should be noted from the cost information, that the first options (3A, 4A, 5A) are relatively high because they include the full cost for replacing the roof over each zone and structurally repairing the floors above. We have therefore considered that each zone will be tackled as a complete zone with all floors refurbished.

### 7.5 Zone 1

In order to achieve income and to demonstrate commitment to the refurbishment of The Coal Exchange it is considered that works to complete Zone 1 are the next step

It should be noted that this work will achieve a series of rooms to the same size as the original building. These are a variety of sizes and ideal for small businesses requiring office related uses. None of the rooms are large enough to provide space for large businesses or non office uses.

- Work to all floors in Zone 1
- New roof over Zone 1
- Area of useable space 1,174 sq m, 12,636 sq ft, 33 rooms
- Cost £1,978,000
- Fees @ 15% £297,000

### 7.6 Zone 2, 3 and 4 Strategies

Given the heritage significance of zone 2 it would appear necessary that this is the next zone to be refurbished if the building was to be dealt with in a zone prioritisation order. However, it should be noted that the full cost of refurbishing all floors in this zone is relatively high at £10,086,746. Whilst some of the spaces refurbished are large (eg. hall) most rooms are office sized. We are aware of filming and performance

opportunities for the hall area and the potential income from such uses may offset the relatively high cost of refurbishing this zone.

- Work to all floors in Zone 2
- New roof over Zone 2
- Area of useable space 2980 sq m, 31,538 sq ft, 61 rooms
- Cost £10,086,746
- Fees @ 15% £1,513,000

Zone 3 or 4 could be considered next. Both provide opportunities for the creation of large flexible or bespoke spaces. Zone 3 contains large areas which are inaccessible / dangerous but also includes areas of heritage significance.

- Work to all floors in Zone 3
- New roof to Zone 3
- Area of useable space 2465 sq m, 26,533 sq ft, 56 rooms
- Cost £9,252,000
- Fees @ 15% £1,388,000

Zone 4 has little heritage significance and high levels of damage/decay. Subject to Cadw agreement, this area could be largely demolished to achieve a large area open to the elements. If Zone 4 was refurbished

- Work to all floors in Zone 4
- New roof to Zone 4
- Areas of useable space 1861 sq m, 20,031 sq ft, 41 rooms
- Cost £7,415,000
- Fees @ 15% £1,113,000

If Zone 4 is demolished

- 508 sq m
- 5468 sq ft
- Cost £26,000
- Fees @ 15% £4,000

## 7.7 Front Entrance

Work to Zones 1 and 2 do not include remodelling of the front entrance area externally. This area of the building includes a bomb resistant bunker intended as a shelter in circumstances of an attack. It is recommended that this is demolished along with the current balcony and external paved areas. A high quality plaza capable of providing an external seating area could be provided and allowance of £750,000 is recommended for such work.

## 7.8 Delivery Issues

In order for the Zone 2 hall and associated catering facilities to function an entrance for deliveries with access to a goods lift needs to be provided. This could be achieved by providing an entrance and service tunnel through Zone 4 to a goods lift in Zone 2 kitchen/hall. A cost allowance of £400,000 is recommended for this work.


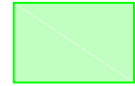




## 7.9 Phasing Summary

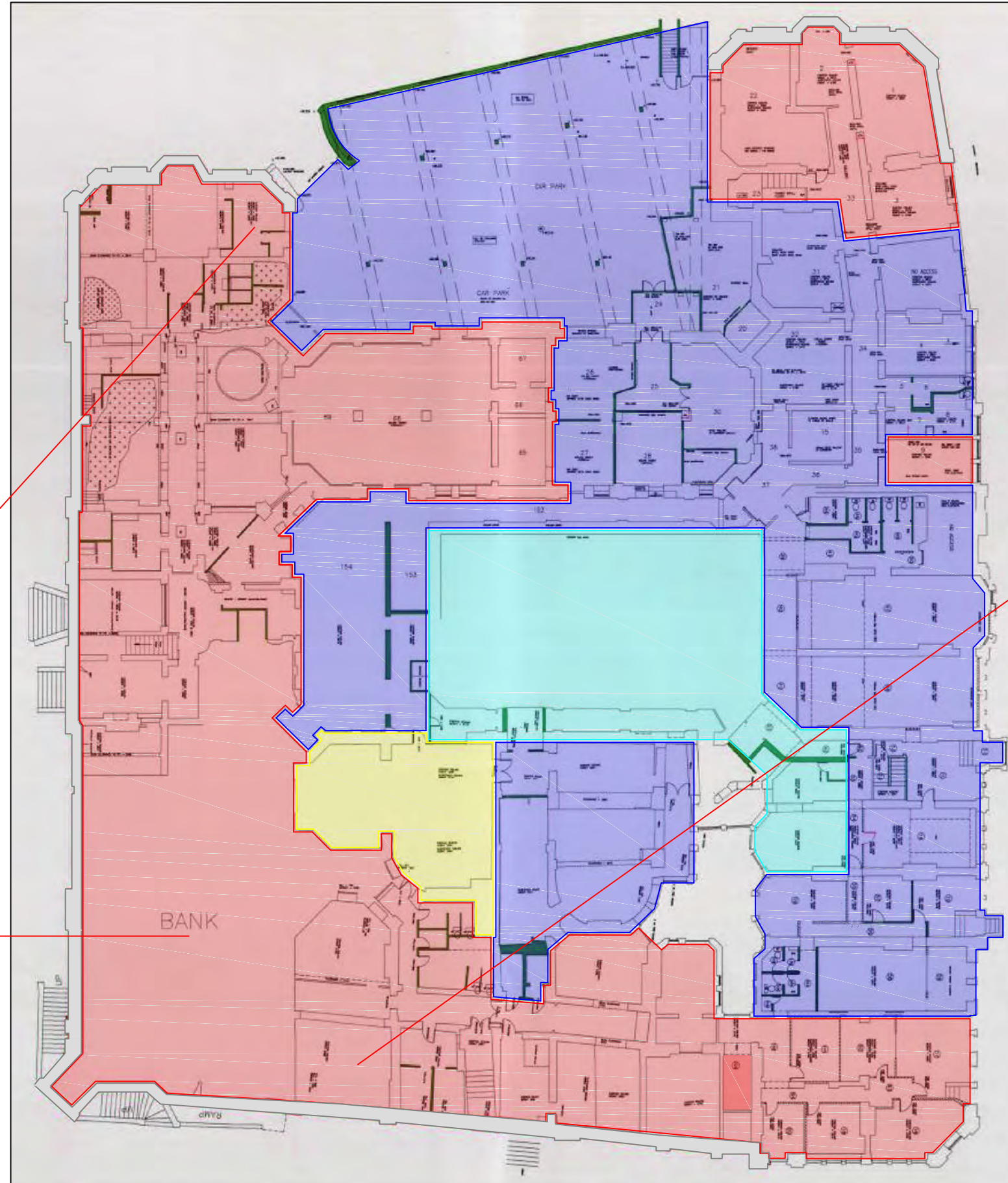
Phase	Works	Costs £k	Fees £k	Totals £k	Cummulative Totals £k
1	Investigations and Surveying (7.2)	-	200	200	200
2	First Works (7.3)	3,155	474	3,629	3,829
3	Zone 1 (7.5)	1,978	297	2,275	6,104
4	Zone 2 (7.6)	10,087	1,513	11,600	17,704
5	Entrance Area (7.7)	750	112	862	18,567
6	Delivery / Goods Access (7.8)	400	60	460	19,027
7	Zone 3 (7.6)	9,252	1,378	10,640	29,667
8	Zone 4 (7.6)	7,415	1,113	8,528	38,195
8	Zone 4 demolition Alternative (7.6)	187	280	2,155	

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## Appendix A Category Plans

Pack Page 103

-  Category 1 Areas currently in use as office accommodation that would require 'minor' repairs.
-  Category 2 Areas which can be brought back into temporary use with 'minor' repairs.
-  Category 3 Areas which are capable of being economically repaired.
-  Category 4 Areas which are not capable of reasonable economic repair.
-  No access due to dangerous structure
-  No access

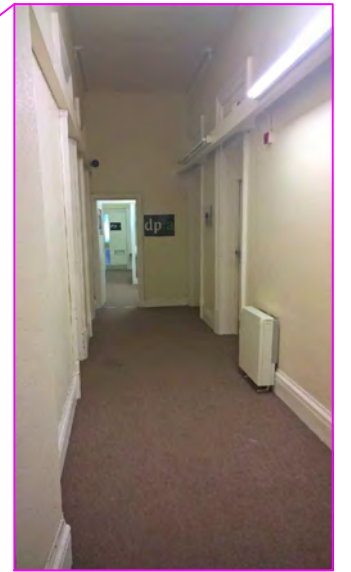
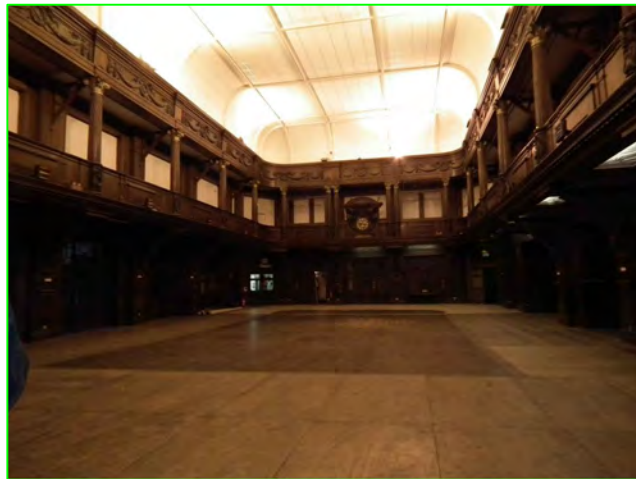


Client			
Welsh Government			
Project			
Coal Exchange Feasibility Study			
Drawing		Drawing no.	
Basement with categories		CE/C01	
Scale @ A3	Drawn	Checked	Approved
NTS	SP		
Project No.		Date	
CS/079052		02/06/2015	
BS1192 Compliant rev			

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- Category 1** Areas currently in use as office accommodation that would require 'minor' repairs.
- Category 2** Areas that can be brought back into temporary use with 'minor' repairs.
- Category 3** Areas which are capable of being economically repaired.
- Category 4** Areas which are not capable of reasonable economic repair.
- No access due to dangerous structure
- No access

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Client			
Welsh Government			
Project			
Coal Exchange Feasibility Study			
Drawing	Drawing no.		
Ground Floor with categories	CE/C02		
Scale @ A3	Drawn	Checked	Approved
NTS	SP		
Project No.	Date		
CS/079052	02/06/2015		
BS1192 Compliant rev			

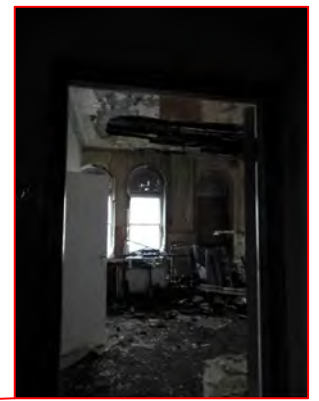
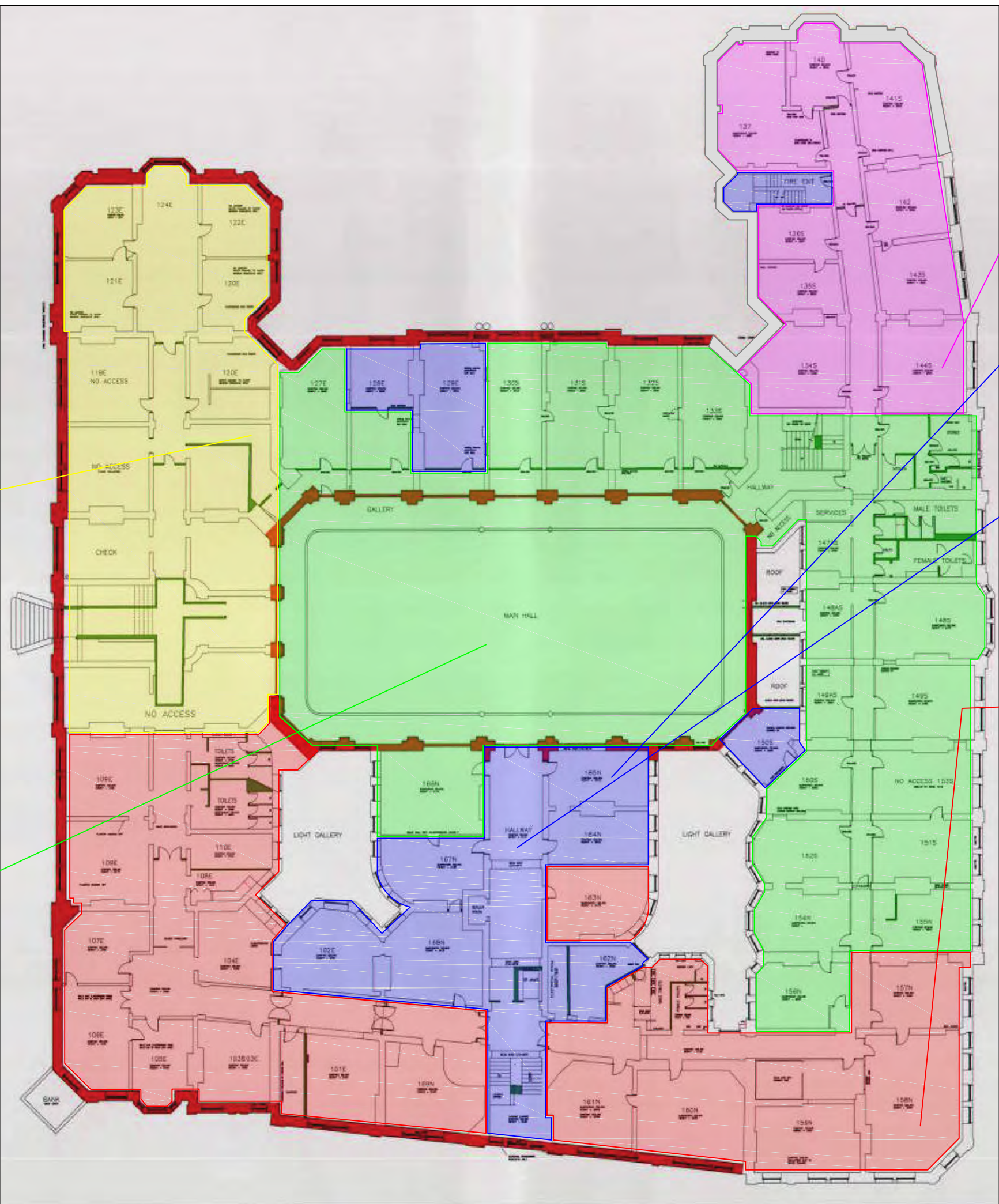
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Print Date: 04/06/2015 15:08:01

- Category 1 Areas currently in use as office accommodation that would require 'minor' repairs.
- Category 2 Areas that can be brought back into temporary use with 'minor' repairs.
- Category 3 Areas which are capable of being economically repaired.
- Category 4 Areas which are not capable of reasonable economic repair.
- No access due to dangerous structure
- No access



Client			
Welsh Government			
Project			
Coal Exchange Feasibility Study			
Drawing		Drawing no.	
First Floor with categories		CE/C03	
Scale @ A3	Drawn	Checked	Approved
NTS	SP		
Project No.		Date	
CS/079052		02/06/2015	
BS1192 Compliant rev			

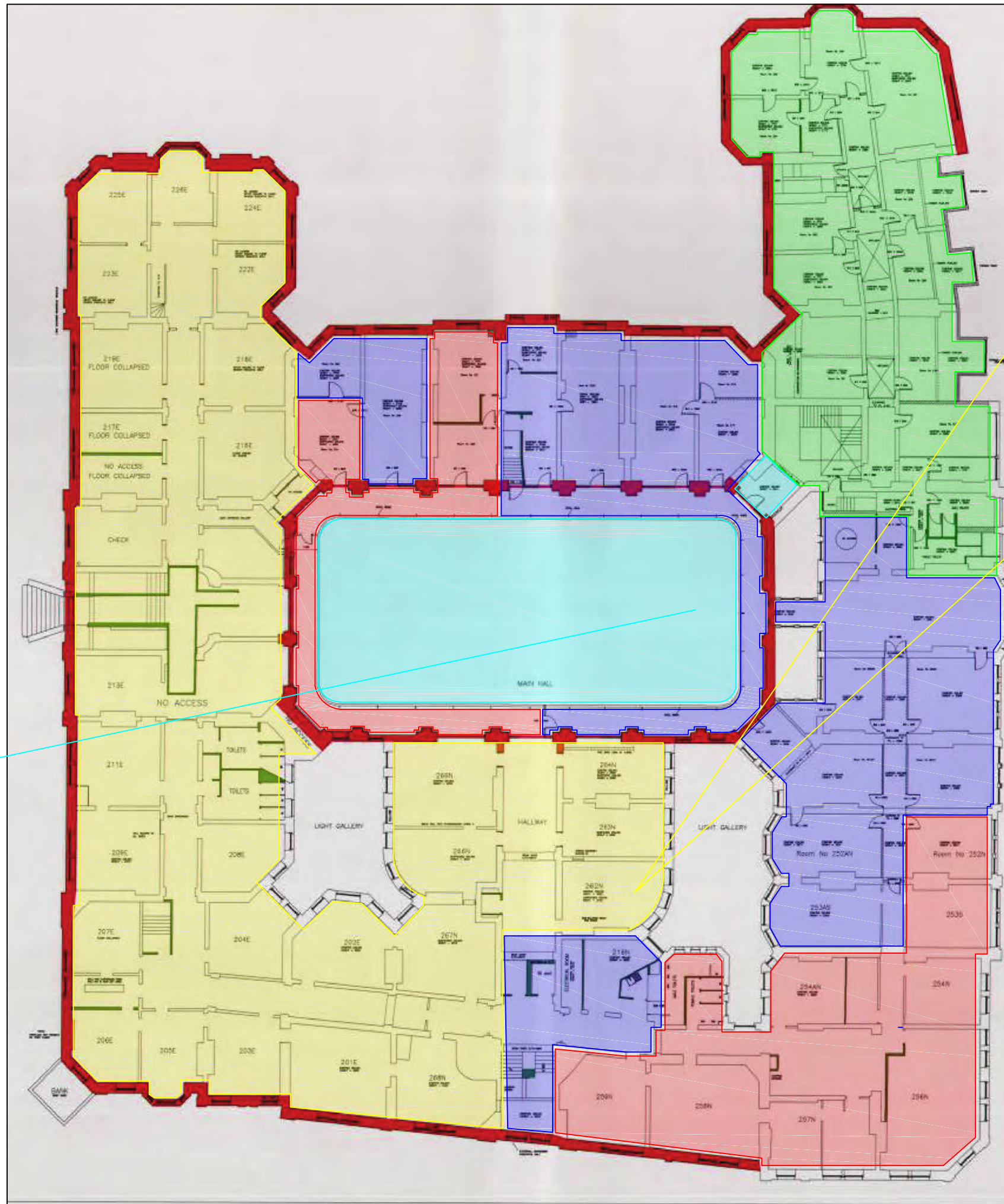
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- Category 1** Areas currently in use as office accommodation that would require 'minor' repairs.
- Category 2** Areas that can be brought back into temporary use with 'minor' repairs.
- Category 3** Areas which are capable of being economically repaired.
- Category 4** Areas which are not capable of reasonable economic repair.
- No access due to dangerous structure**
- No access**

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Client  
**Welsh Government**

Project  
**Coal Exchange Feasibility Study**

Drawing **Second Floor with categories** Drawing no. **CE/C04**

Scale @ A3 Drawn Checked Approved


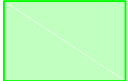




NTS SP

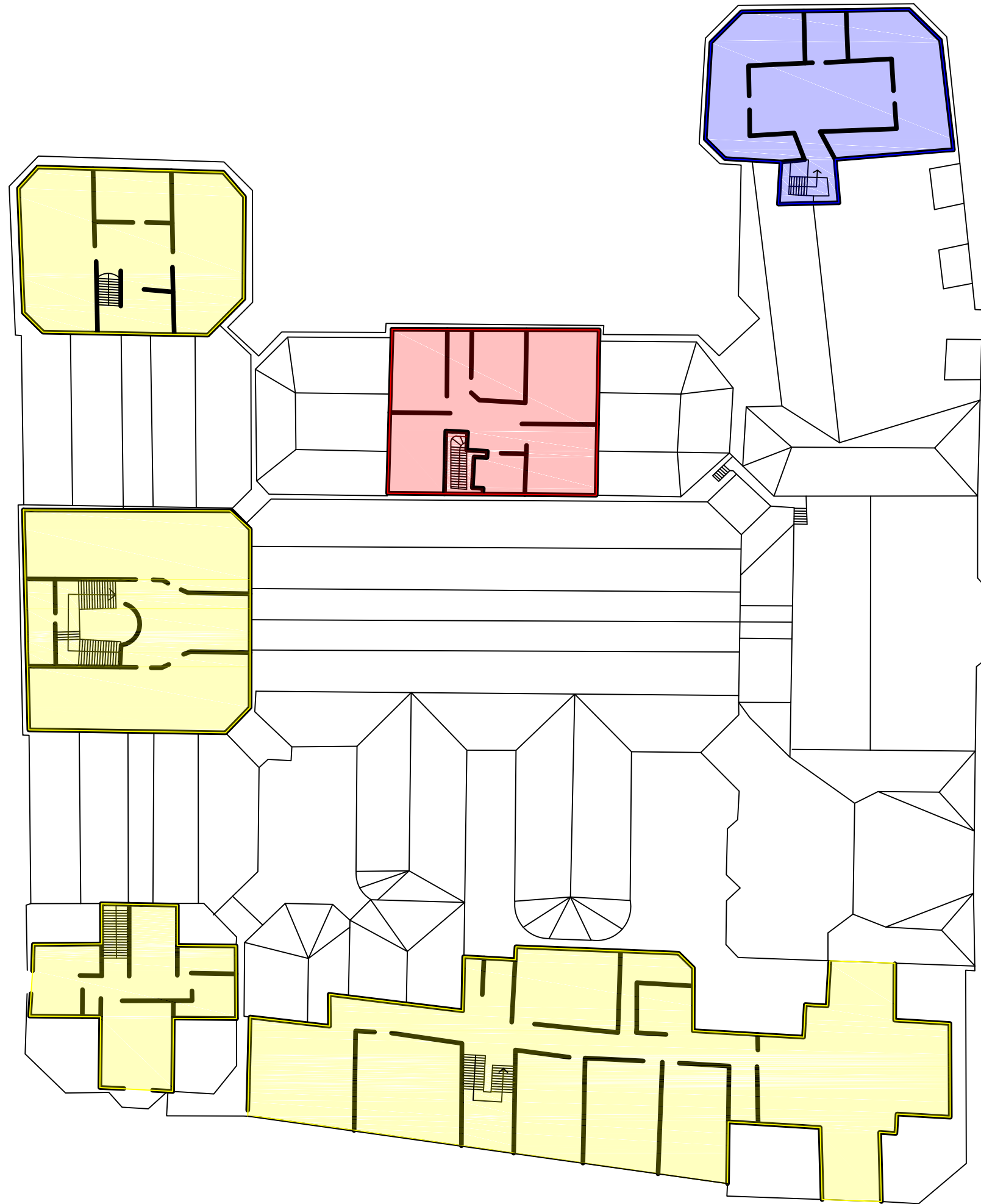
Project No. **CS/079052** Date **02/06/2015**

BS1192 Compliant  
rev

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-  Category 1 Areas currently in use as office accommodation that would require 'minor' repairs.
-  Category 2 Areas that can be brought back into temporary use with 'minor' repairs.
-  Category 3 Areas which are capable of being economically repaired.
-  Category 4 Areas which are not capable of reasonable economic repair.
-  No access due to dangerous structure
-  No access



Pack Page 108

Client  
**Welsh Government**

Project  
**Coal Exchange Feasibility Study**

Drawing **Third Floor with categories** Drawing no. **CE/C05**

Scale @ A3 Drawn Checked Approved

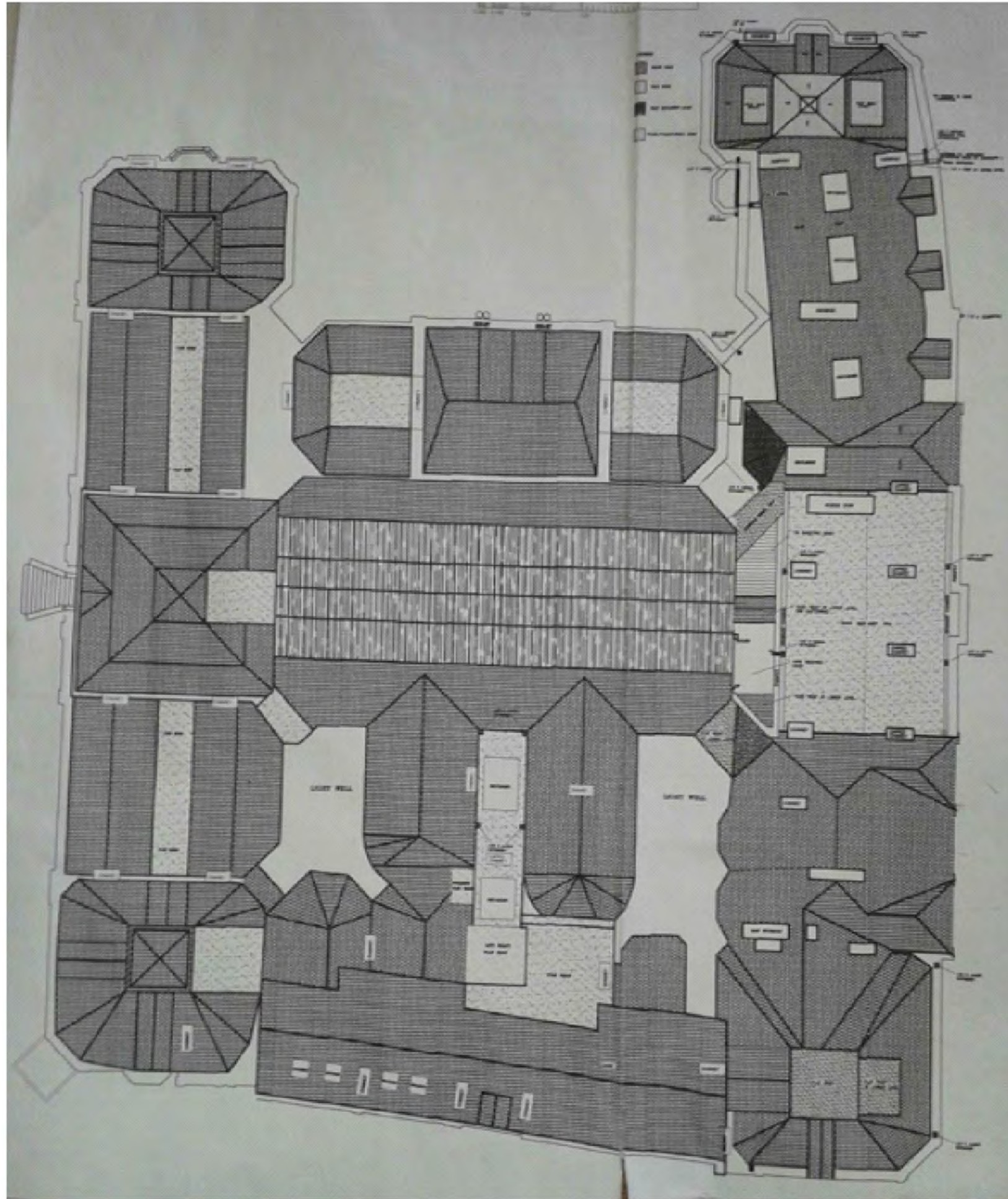
NTS SP

Project No. **CS/079052** Date **02/06/2015**

BS1192 Compliant  
rev

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All roof areas were not accessed due to dangerous structure

Client			
Welsh Government			
Project			
Coal Exchange Feasibility Study			
Drawing		Drawing no.	
Roof		CE/C06	
Scale @ A3	Drawn	Checked	Approved
NTS	SP		
Project No.		Date	
CS/079052		02/06/2015	
BS1192 Compliant rev			

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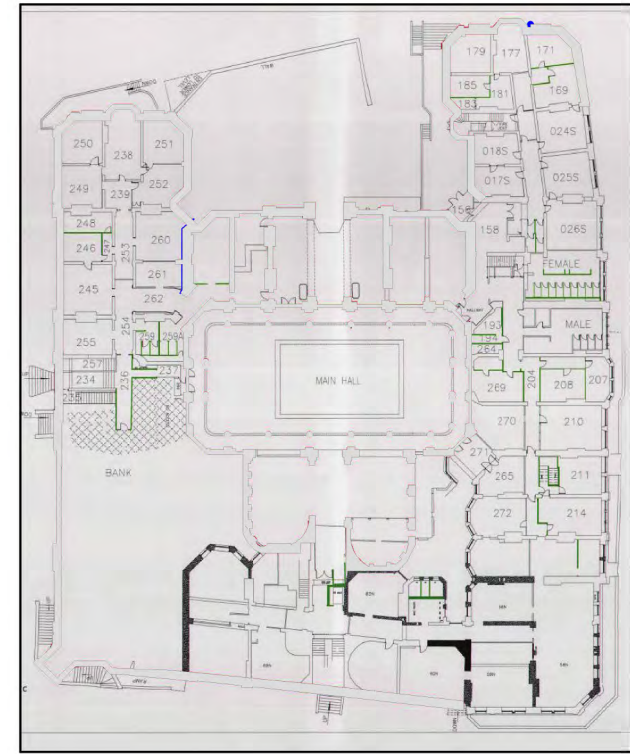
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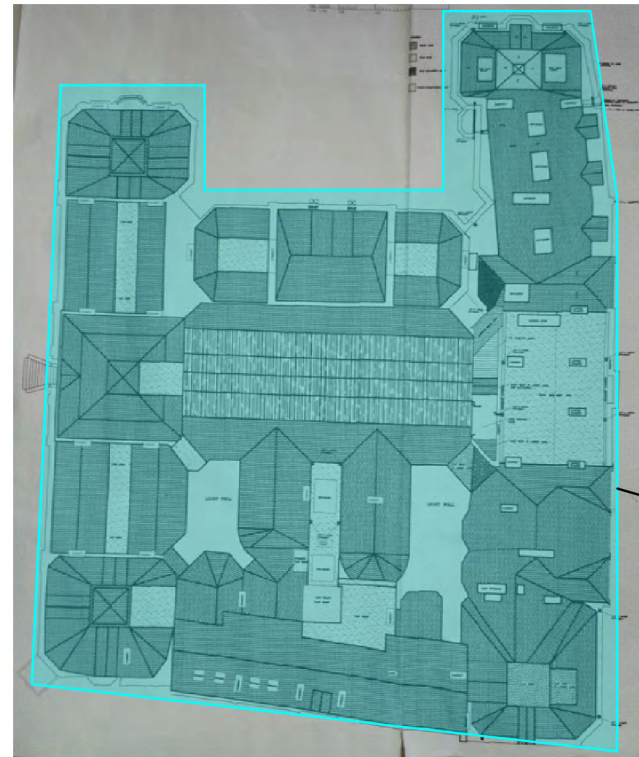
## Appendix B Zone Plans

### Option 1A

No internal areas, facade retention to all zones and temporary roof over all zones.



General Plan



Roof Plan

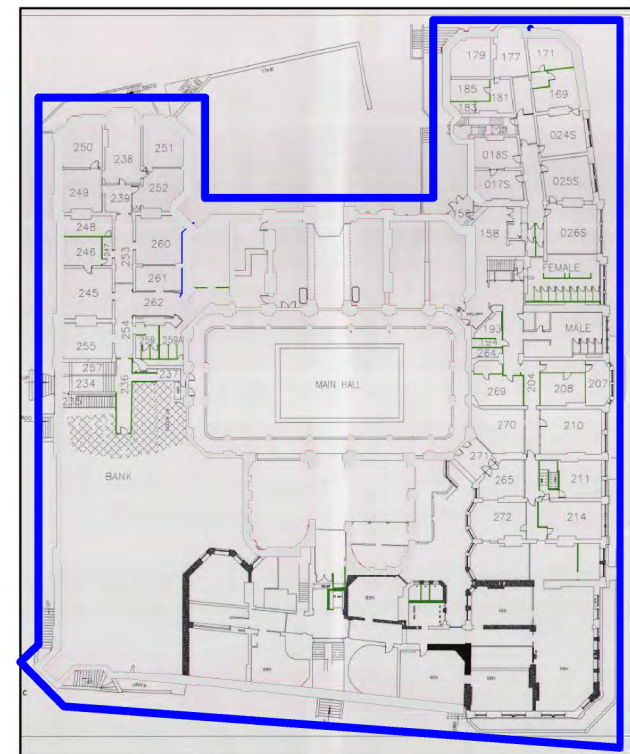
#### Costs

Temporary roof over all zones	£1,280,000
Facade retention	£750,000
Basement	£1,000,000
<b>Cumulative Total</b>	<b>£3,030,000</b>

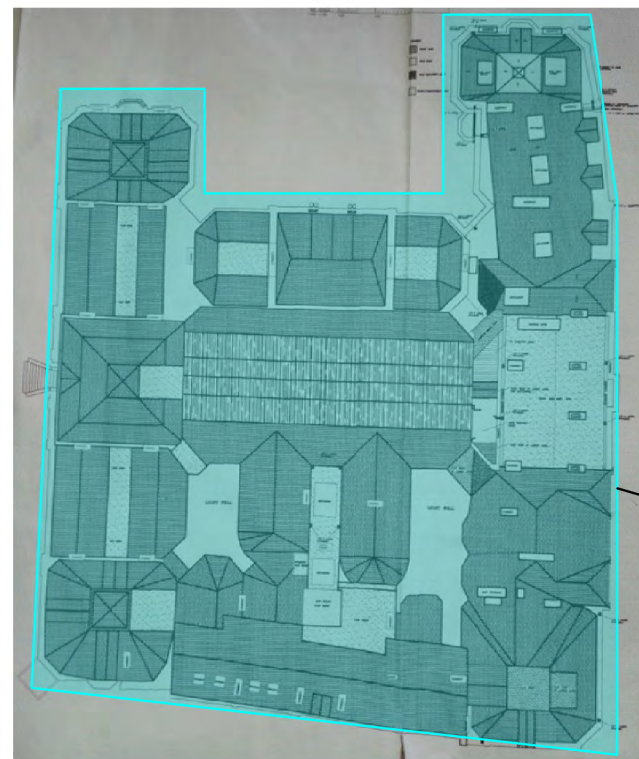
Temporary roof over all zones

### Option 1B

No internal areas, facade retention with building wrap to all zones and temporary roof over all zones.



General Plan



Roof Plan

#### Costs

Temporary roof over all zones	£1,280,000
Facade retention	£750,000
Building wrap	£125,000
Basement	£1,000,000
<b>Cumulative Total</b>	<b>£3,155,000</b>

Temporary roof over all zones

Client  
Welsh Government

Project  
Coal Exchange Feasibility Study

Drawing  
Option 1A & 1B

Drawing no.  
CE/Z01

Scale @ A3  
NTS

Drawn  
SP

Checked  
SP

Approved

Project No.  
CS/079052

Date  
02/06/2015

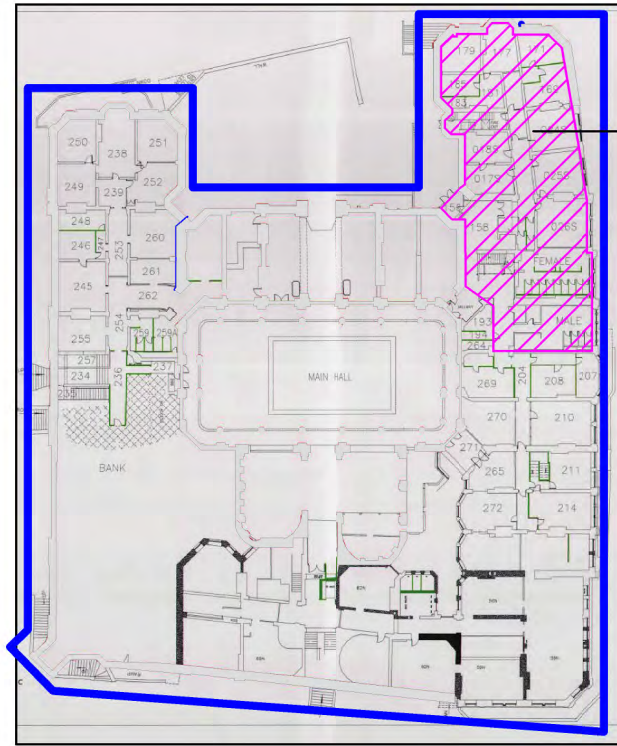
BS1192 Compliant  
rev

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Building Consultancy

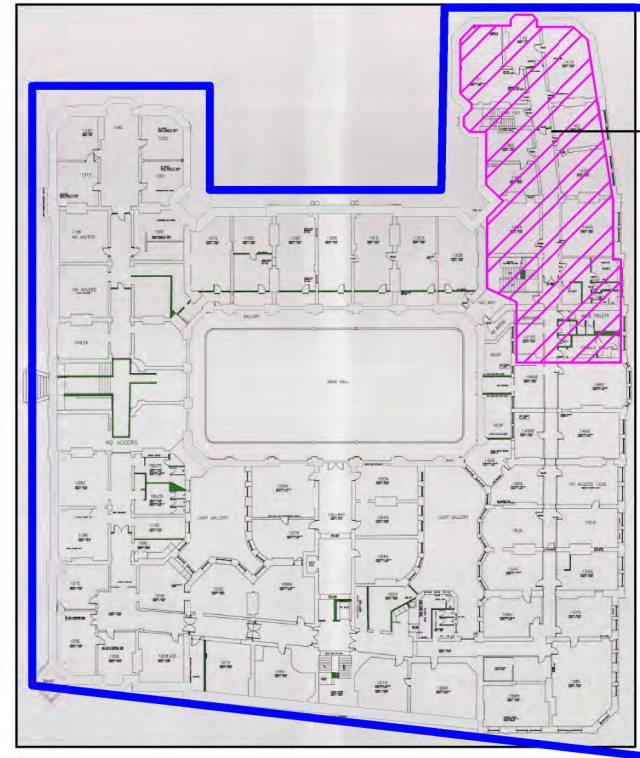
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## Option 2

Refurbishment of entire Zone 1 area to enable occupation, including roof. Building wrap to circumference of the building and temporary roof over all zones.



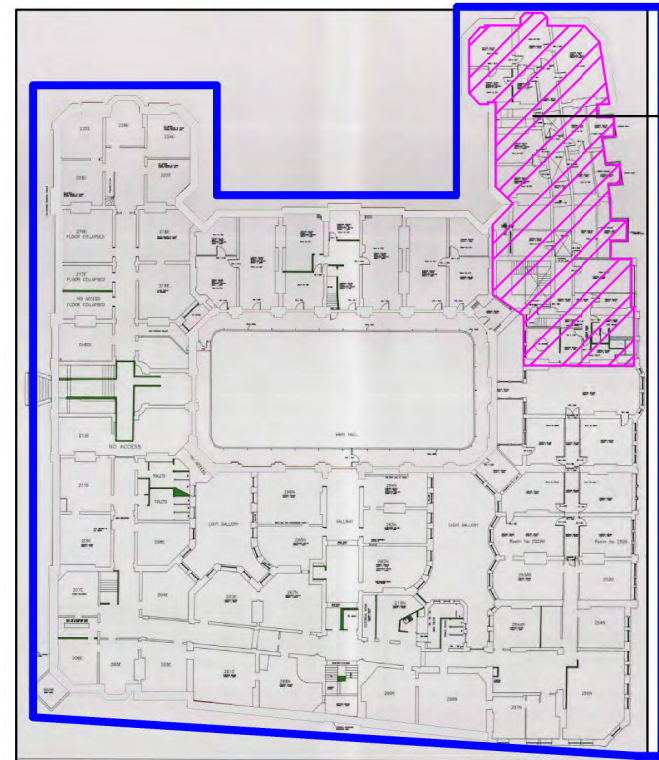
Zone 1  
11 rooms



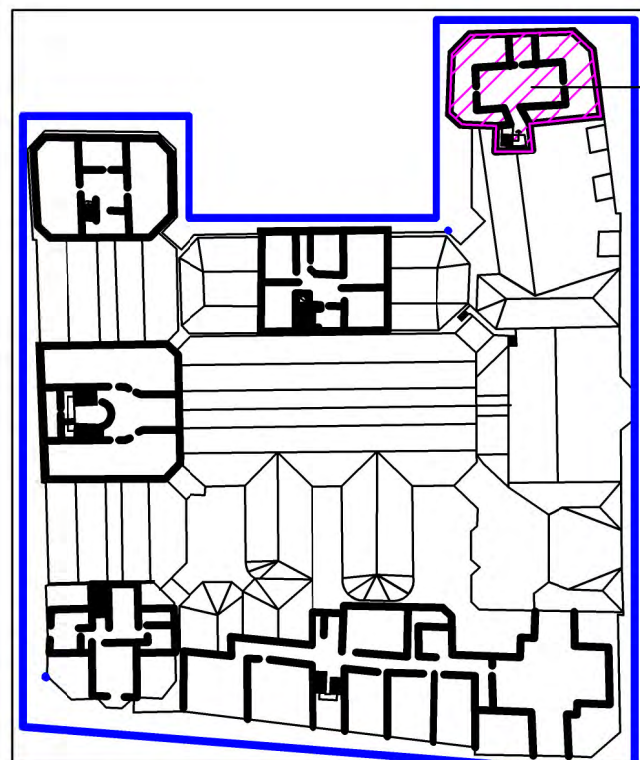
Zone 1  
9 rooms

Ground Floor

First Floor



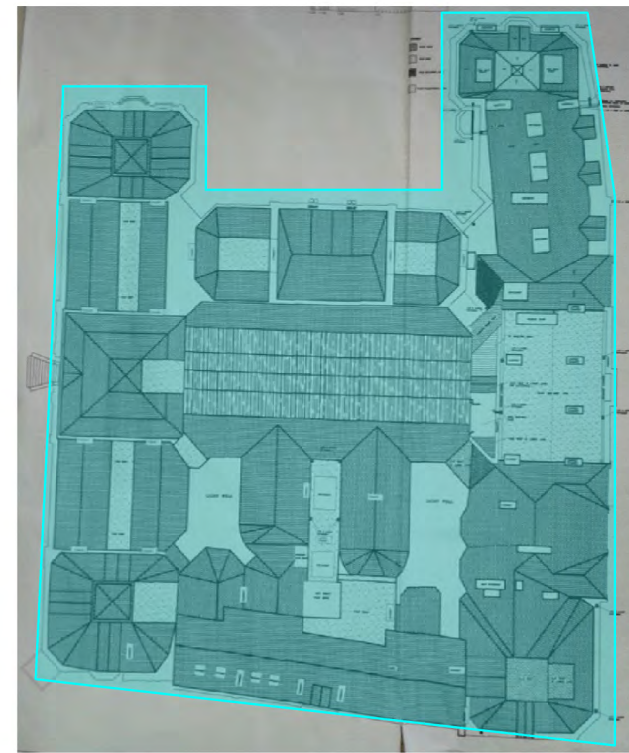
Zone 1  
12 rooms



Zone 1  
Flat

Second Floor


Third Floor



Roof Plan

Temporary roof over all zones

### Key

 Zone 1 - full refurbishment

 Building wrap

### Costs

Zone 1	£778,211
Roof refurbishment to Zone 1	£876,300
Temporary roof over all zones	£1,280,000
Facade retention	£750,000
Building wrap	£125,000
DDA compliance	£176,700
Other compliance requirements	£147,250
Allowance for basement	£1,000,000
<b>Cumulative Total</b>	<b>£5,133,461</b>

### Floor Areas

Floor Level	Zone 1
Ground	381m <sup>2</sup> / 4101 sq ft
First	371m <sup>2</sup> / 3993 sq ft
Second	322m <sup>2</sup> / 3466 sq ft
Third	100m <sup>2</sup> / 1076 sq ft
<b>Total</b>	<b>1174m<sup>2</sup> / 12636 sq ft</b>

Client  
Welsh Government

Project  
Coal Exchange Feasibility Study

Drawing  
Option 2

Drawing no.  
CE/Z02

Scale @ A3  
NTS

Drawn  
SP

Checked

Approved

Project No.  
CS/079052

Date  
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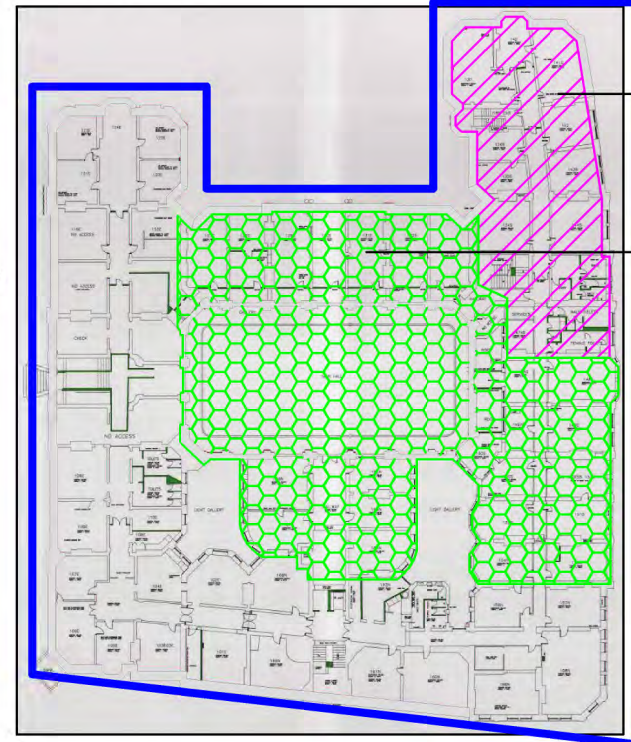
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### Option 3A

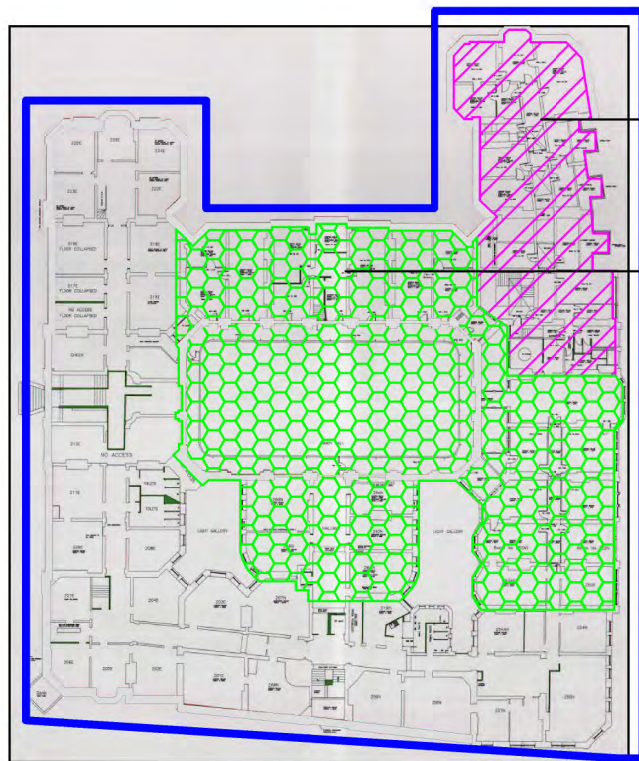
Refurbishment of all areas to Zone 1 (as option 2) and Zone 2 ground floor to enable occupation, with upper floors to Zone 2 structurally complete. Includes refurbishment of roof to Zone 1 and 2. Building wrap to Zones 2, 3 and 4 and temporary roof over all zones.



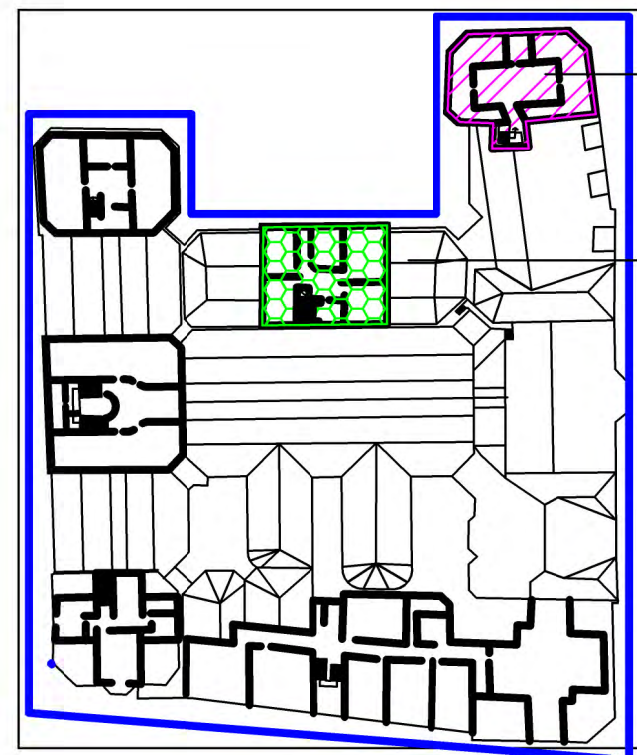
Ground Floor



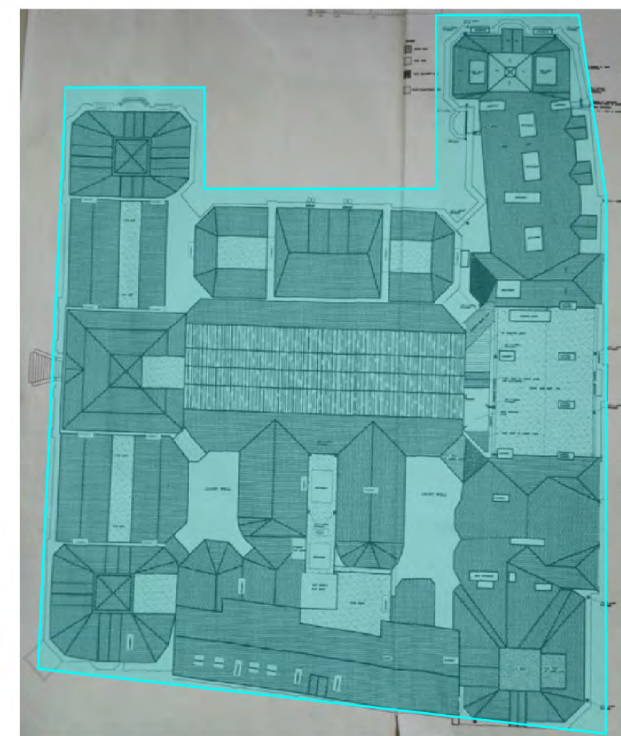
First Floor



Second Floor







Third Floor



Roof Plan

Temporary roof to all zones

#### Key

-  Zone 1 - full refurbishment
-  Zone 2 - full refurbishment
-  Zone 2 - structurally complete
-  Building wrap

#### Costs

Zone 1	£778,211
Zone 2	£2,183,466
Roof refurbishment to Zones 1&2	£5,188,800
Temporary roof over all zones	£1,280,000
Facade retention	£750,000
Building wrap	£125,000
DDA compliance	£1,231,200
Other compliance requirements	£1,026,000
Allowance for basement	£1,000,000
<b>Cumulative Total</b>	<b>£13,562,677</b>

#### Floor Areas

Floor Level	Zone 1	Zone 2
Ground	381m <sup>2</sup> / 4101 sq ft	1150m <sup>2</sup> / 12378 sq ft
First	371m <sup>2</sup> / 3993 sq ft	782m <sup>2</sup> / 8417 sq ft
Second	322m <sup>2</sup> / 3466 sq ft	1188m <sup>2</sup> / 12787 sq ft
Third	100m <sup>2</sup> / 1076 sq ft	106m <sup>2</sup> / 1141 sq ft
<b>Total</b>	<b>1174m<sup>2</sup> / 12636 sq ft</b>	<b>3226m<sup>2</sup> / 34723 sq ft</b>

Client  
Welsh Government

Project  
Coal Exchange Feasibility Study

Drawing  
Option 3A

Drawing no.  
CE/Z03

Scale @ A3  
NTS

Drawn  
SP

Checked

Approved

Project No.  
CS/079052

Date  
02/06/2015

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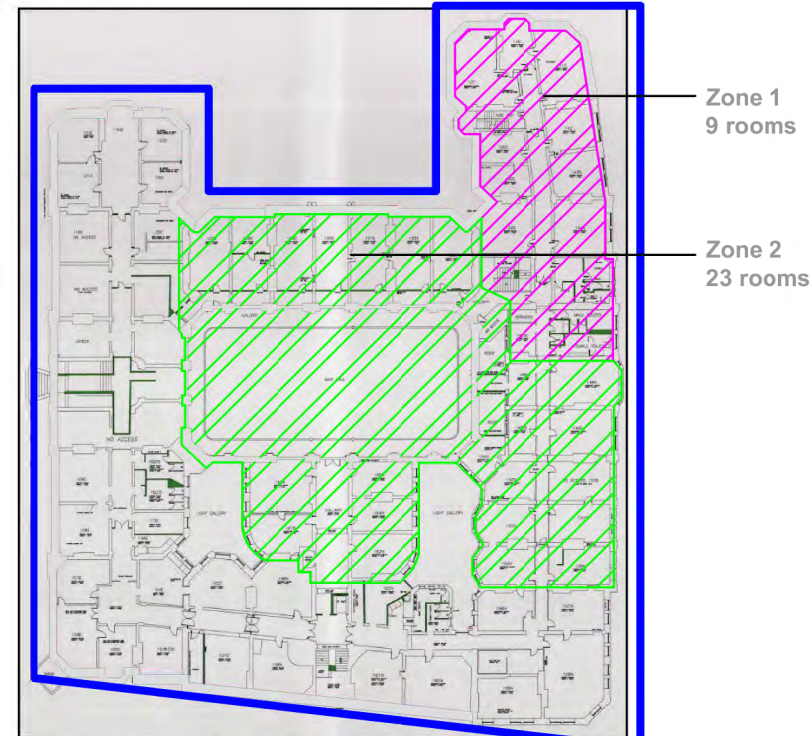
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### Option 3B

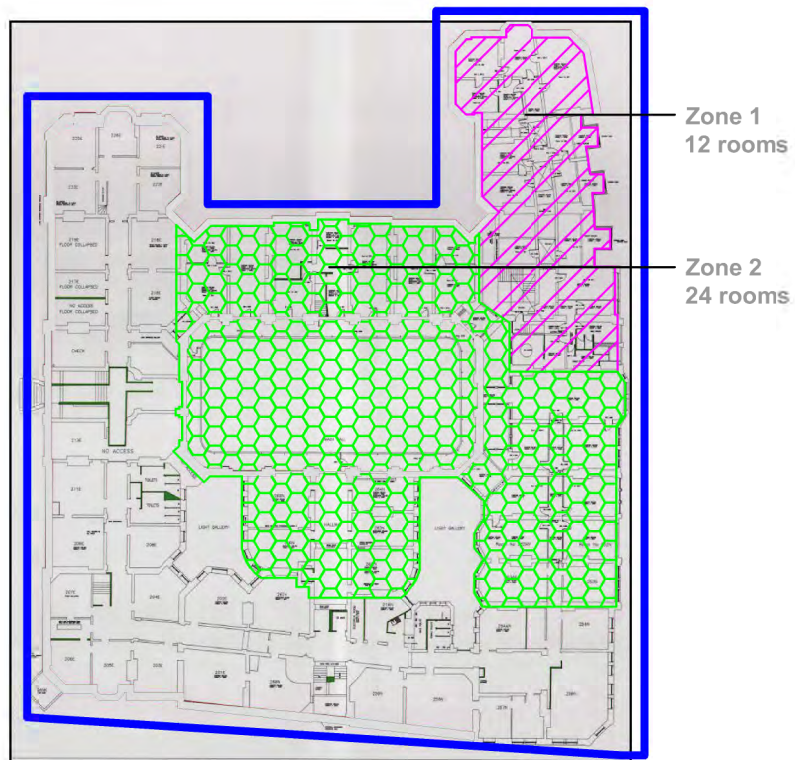
Refurbishment of Zone 1 ( as option 2) and Zone 2 ground floor and first floor, with upper floors to Zone 2 structurally complete. Includes refurbishment of roof to Zone 1 and 2. Building wrap to Zones 2, 3 and 4 and temporary roof over all zones.



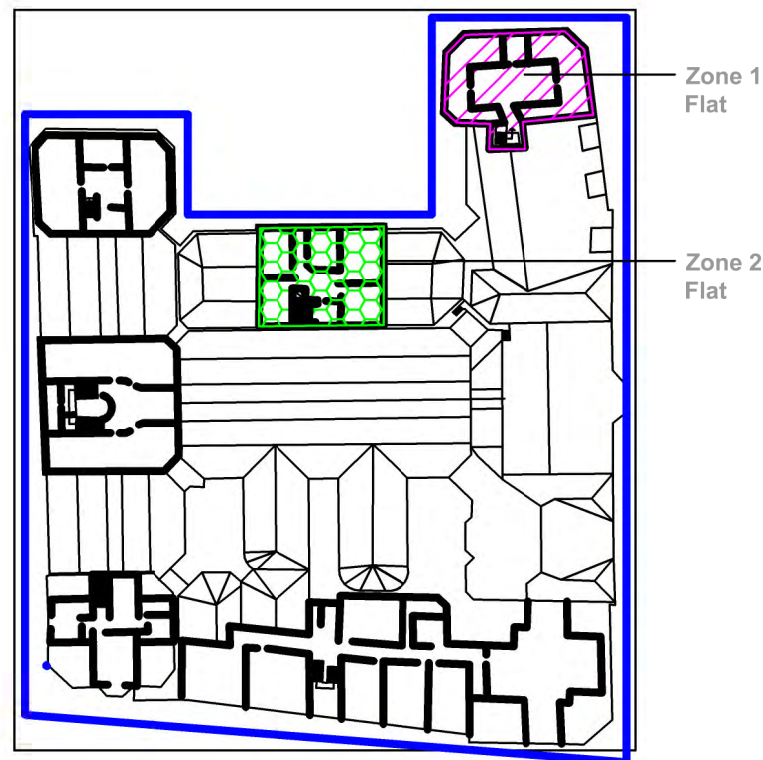
Ground Floor



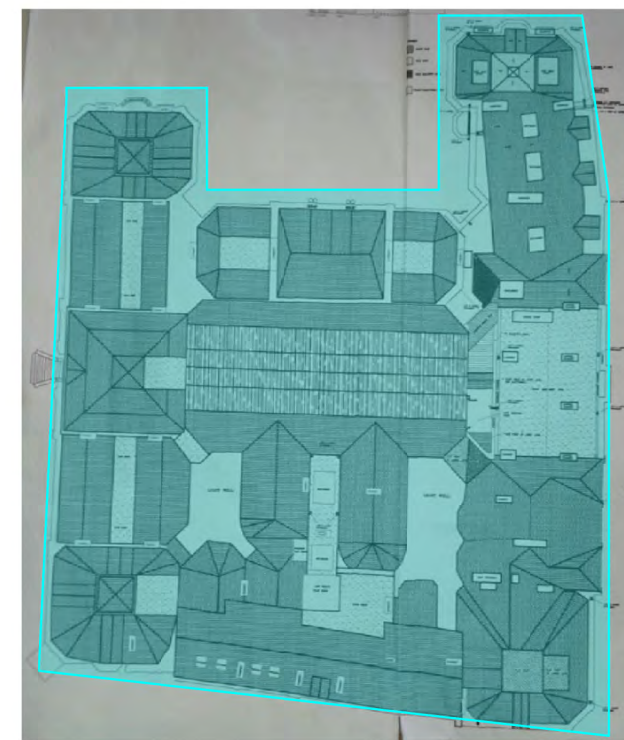
First Floor



Second Floor







Third Floor



Roof Plan  
Temporary roof to all areas

#### Key

-  Zone 1 - full refurbishment
-  Zone 2 - full refurbishment
-  Zone 2 - structurally complete
-  Building wrap

#### Costs

Zone 1	£778,211
Zone 2	£2,635,774
Roof refurbishment to Zone 1 & 2	£5,188,800
Temporary roof over all zones	£1,280,000
Facade retention	£750,000
Building wrap	£125,000
DDA compliance	£1,231,200
Other compliance requirements	£1,026,000
Allowance for basement	£1,000,000
<b>Cumulative Total</b>	<b>£14,014,985</b>

#### Floor Areas

Floor Level	Zone 1	Zone 2
Ground	381m <sup>2</sup> / 4101 sq ft	1150m <sup>2</sup> / 12378 sq ft
First	371m <sup>2</sup> / 3993 sq ft	782m <sup>2</sup> / 8417 sq ft
Second	322m <sup>2</sup> / 3466 sq ft	1188m <sup>2</sup> / 12787 sq ft
Third	100m <sup>2</sup> / 1076 sq ft	106m <sup>2</sup> / 1141 sq ft
<b>Total</b>	<b>1174m<sup>2</sup> / 12636 sq ft</b>	<b>3226m<sup>2</sup> / 34723 sq ft</b>

Client  
Welsh Government

Project  
Coal Exchange Feasibility Study

Drawing  
Option 3B

Drawing no.  
CE/Z04

Scale @ A3  
NTS

Drawn  
SP

Checked

Approved

Project No.  
CS/079052

Date  
02/06/2015

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

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### Option 3C

Refurbishment of Zone 1 and Zone 2, including roof.  
 Building wrap to Zones 2, 3 and 4 and temporary roof over all zones.

**Key**

-  Zone 1 - full refurbishment
-  Zone 2 - full refurbishment
-  Building wrap



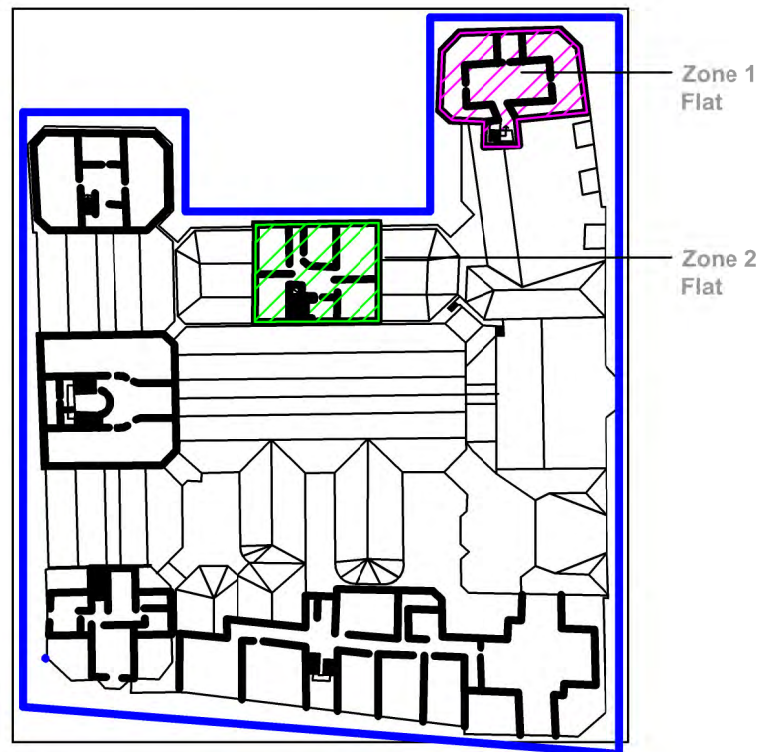
Ground Floor



First Floor



Second Floor



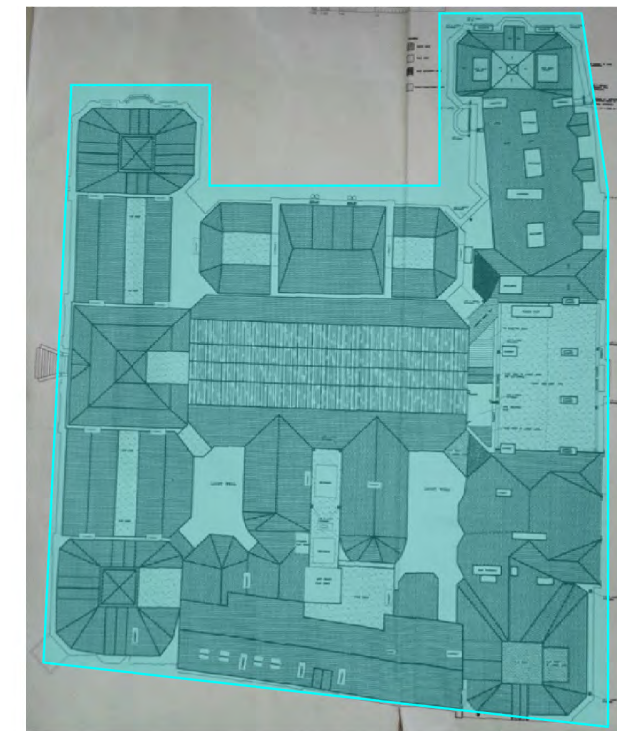
Third Floor

### Costs

Zone 1	£778,211
Zone 2	£3,840,996
Roof refurbishment to Zone 1 & 2	£5,188,800
Temporary roof to all zones	£1,280,000
Facade retention	£750,000
Building wrap	£125,000
DDA compliance	£1,231,200
Other compliance requirements	£1,026,000
Allowance for basement	£1,000,000
<b>Cumulative Total</b>	<b>£15,220,207</b>

### Floor Areas

Floor Level	Zone 1	Zone 2
Ground	381m <sup>2</sup> / 4101 sq ft	1150m <sup>2</sup> / 12378 sq ft
First	371m <sup>2</sup> / 3993 sq ft	782m <sup>2</sup> / 8417 sq ft
Second	322m <sup>2</sup> / 3466 sq ft	1188m <sup>2</sup> / 12787 sq ft
Third	100m <sup>2</sup> / 1076 sq ft	106m <sup>2</sup> / 1141 sq ft
<b>Total</b>	<b>1174m<sup>2</sup> / 12636 sq ft</b>	<b>3226m<sup>2</sup> / 34723 sq ft</b>



Roof Plan

Temporary roof to all zones

Client			
Welsh Government			
Project			
Coal Exchange Feasibility Study			
Drawing		Drawing no.	
Option 3C		CE/Z05	
Scale @ A3	Drawn	Checked	Approved
NTS	SP		
Project No.		Date	
CS/079052		02/06/2015	
BS1192 Compliant rev			

## CAPITA Building Consultancy

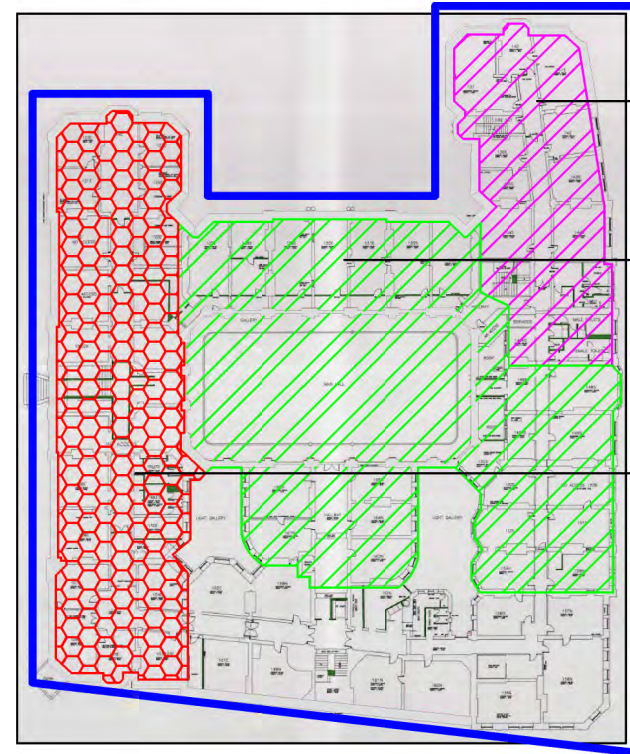
Ty Menter, Unit G1, Main Avenue, Treforest Industrial Estate,  
 Treforest, CF37 5YL - 01443 823200  
 www.capitaproperty.co.uk  
 Capita Property and Infrastructure Ltd.

## Option 4A

Refurbishment of all areas to Zone 1 and Zone 2 (as option 3C) and Zone 3 (ground floor) with upper floors to Zone 3 structurally complete. Includes refurbishment of roof to Zones 1, 2 and 3. Building wrap to Zones 3 and 4 and temporary roof over all zones.



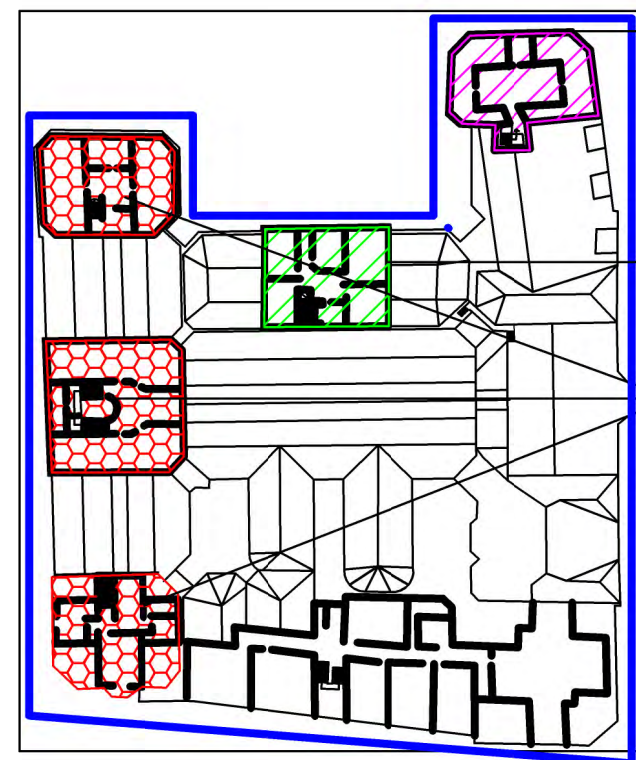
Ground Floor



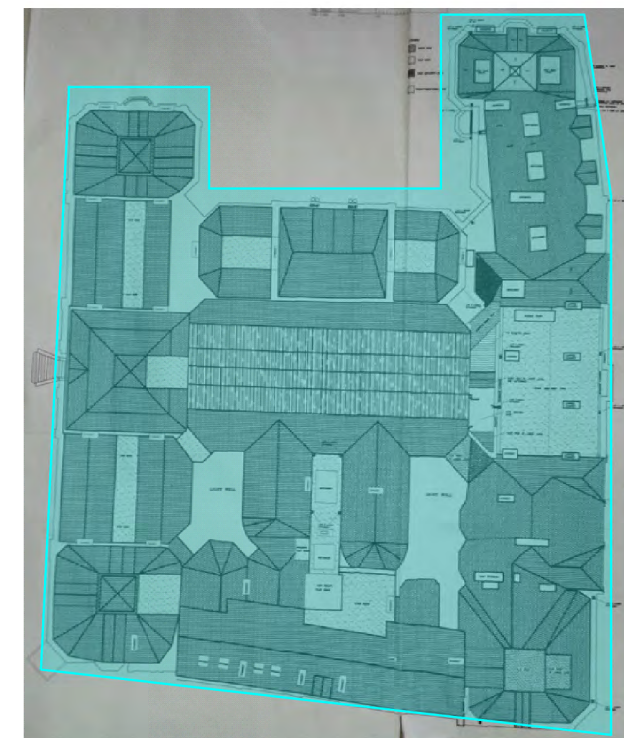
First Floor



Second Floor








Third Floor



Roof Plan

Temporary roof to all areas

### Key

-  Zone 1 - full refurbishment
-  Zone 2 - full refurbishment
-  Zone 3 - full refurbishment
-  Zone 3 - structurally complete
-  Building wrap

### Costs

Zone 1	£778,211
Zone 2	£3,840,996
Zone 3	£3,664,167
Roof refurbishment to Zones 1,2 and 3	£6,900,000
Temporary roof to all zones	£1,280,000
Facade retention	£750,000
Building wrap	£125,000
DDA compliance	£1,970,700
Other compliance requirements	£1,642,250
Allowance for basement	£1,000,000
<b>Cumulative Total</b>	<b>£21,951,324</b>

### Floor Areas

Floor Level	Zone 1	Zone 2	Zone 3
Ground	381m <sup>2</sup> / 4101 sq ft	1150m <sup>2</sup> / 12378 sq ft	744m <sup>2</sup> / 8008 sq ft
First	371m <sup>2</sup> / 3993 sq ft	782m <sup>2</sup> / 8417 sq ft	684m <sup>2</sup> / 7363 sq ft
Second	322m <sup>2</sup> / 3466 sq ft	1188m <sup>2</sup> / 12787 sq ft	684m <sup>2</sup> / 7363 sq ft
Third	100m <sup>2</sup> / 1076 sq ft	106m <sup>2</sup> / 1141 sq ft	353m <sup>2</sup> / 3799 sq ft
<b>Total</b>	<b>1174m<sup>2</sup> / 12636 sq ft</b>	<b>3226m<sup>2</sup> / 34723 sq ft</b>	<b>2465m<sup>2</sup> / 26533 sq ft</b>

Client  
Welsh Government

Project  
Coal Exchange Feasibility Study

Drawing  
Option 4A

Drawing no.  
CE/Z06

Scale @ A3  
NTS

Drawn  
SP

Checked  
SP

Approved  
SP

Project No.  
CS/079052

Date  
02/06/2015

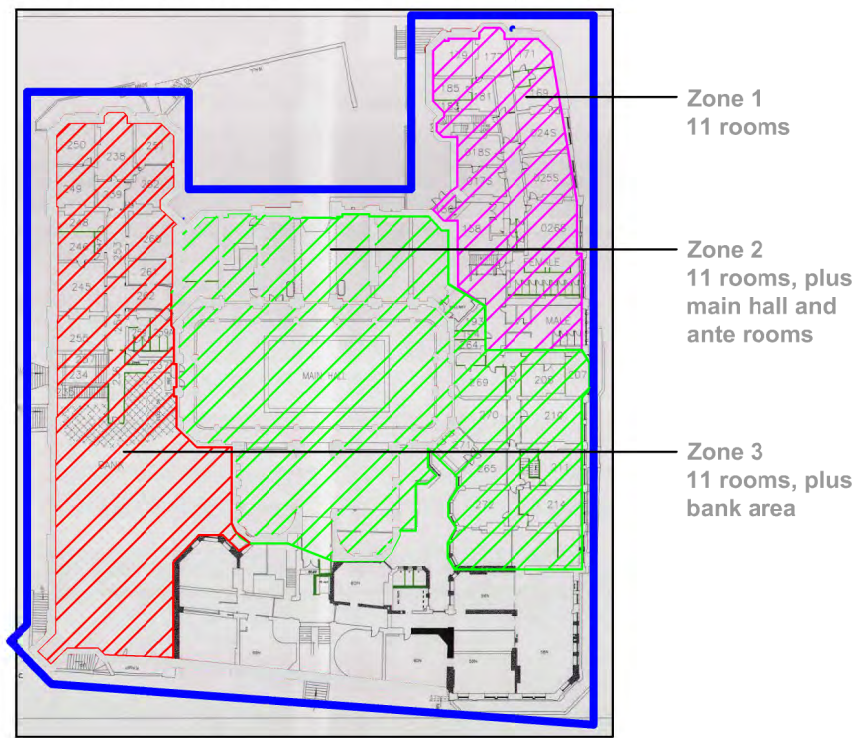
BS1192 Compliant  
rev

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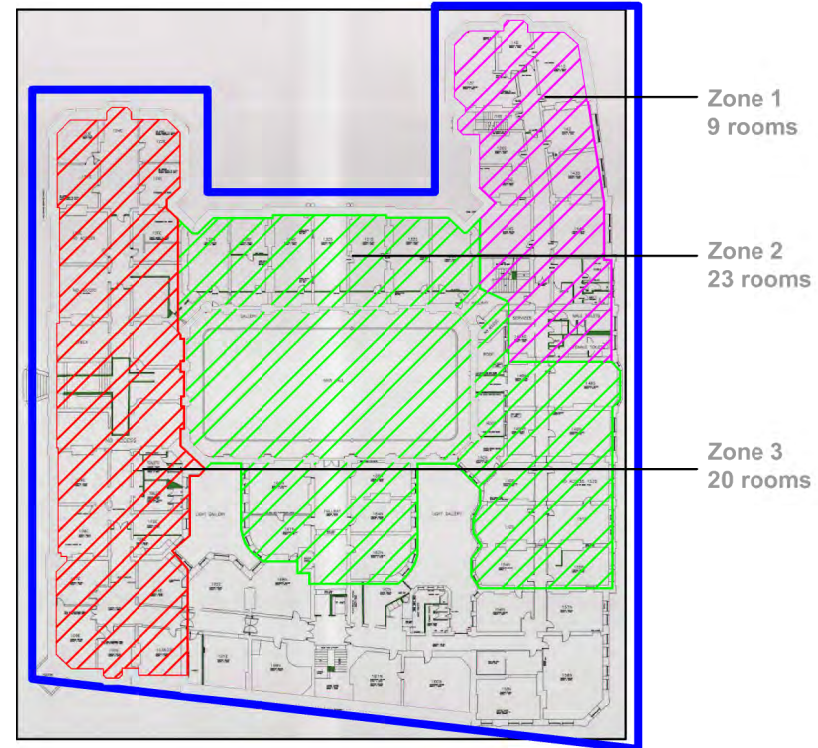
Ty Menter, Unit G1, Main Avenue, Treforest Industrial Estate,  
Treforest, CF37 5YL - 01443 823200  
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Capita Property and Infrastructure Ltd.

## Option 4B

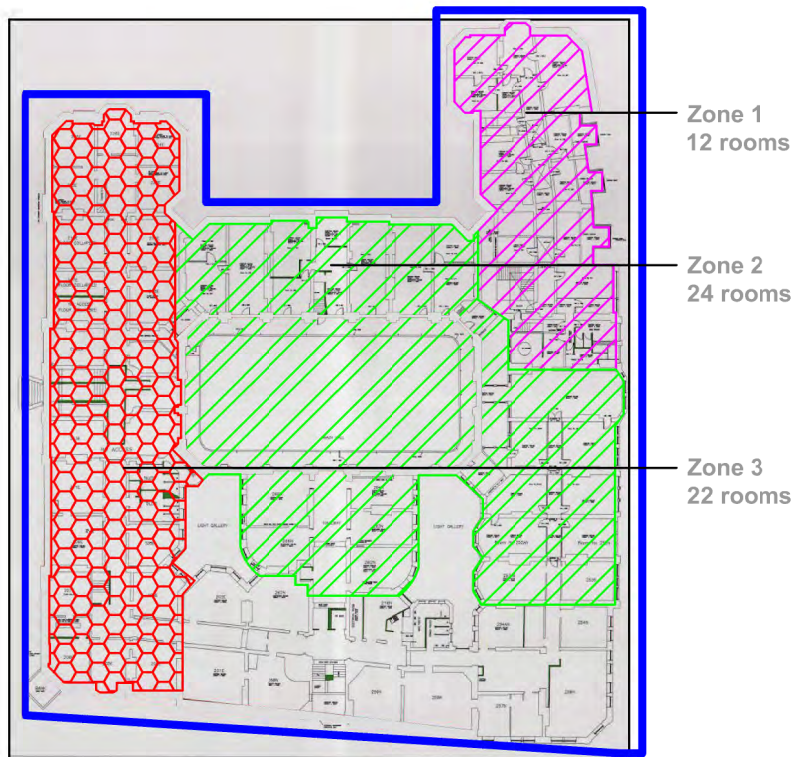
Refurbishment of all areas to Zone 1, Zone 2 ( as option 3C) and Zone 3 ground floor and first floor with the upper floors to Zone 3 structurally complete. Includes refurbishment of roof to Zones 1, 2 and 3. Building wrap to Zones 3 and 4 and temporary roof over all zones.



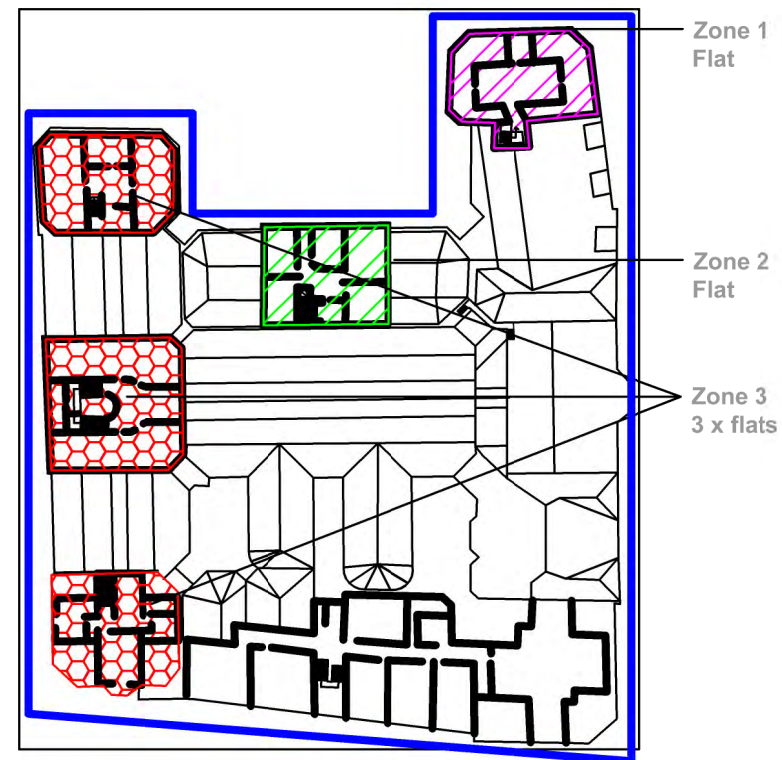
Ground Floor



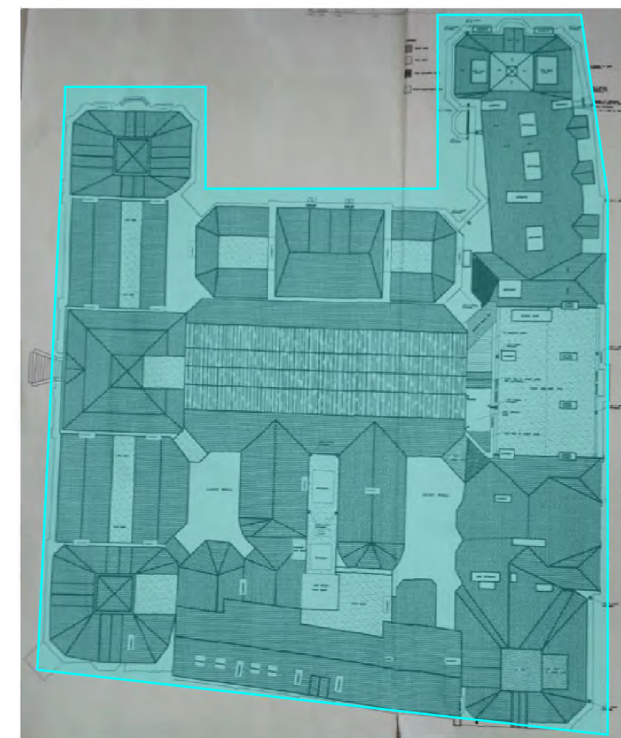
First Floor



Second Floor








Third Floor



Roof Plan

Temporary roof to all zones

### Key

-  Zone 1 - full refurbishment
-  Zone 2 - full refurbishment
-  Zone 3 - full refurbishment
-  Zone 3 - structurally complete
-  Building wrap

### Costs

Zone 1	£778,211
Zone 2	£3,840,996
Zone 3	£4,879,102
Roof refurbishment to Zones 1, 2 & 3	£6,900,000
Temporary roof to all zones	£1,280,000
Facade retention	£750,000
Building wrap	£125,000
DDA compliance	£1,970,700
Other compliance requirements	£1,642,250
Allowance for basement	£1,000,000
<b>Cumulative Total</b>	<b>£23,166,259</b>

### Floor Areas

Floor Level	Zone 1	Zone 2	Zone 3
Ground	381m <sup>2</sup> / 4101 sq ft	1150m <sup>2</sup> / 12378 sq ft	744m <sup>2</sup> / 8008 sq ft
First	371m <sup>2</sup> / 3993 sq ft	782m <sup>2</sup> / 8417 sq ft	684m <sup>2</sup> / 7363 sq ft
Second	322m <sup>2</sup> / 3466 sq ft	1188m <sup>2</sup> / 12787 sq ft	684m <sup>2</sup> / 7363 sq ft
Third	100m <sup>2</sup> / 1076 sq ft	106m <sup>2</sup> / 1141 sq ft	353m <sup>2</sup> / 3799 sq ft
Total	1174m <sup>2</sup> / 12636 sq ft	3226m <sup>2</sup> / 34723 sq ft	2465m <sup>2</sup> / 26533 sq ft

Client  
Welsh Government

Project  
Coal Exchange Feasibility Study

Drawing  
Option 4B

Drawing no.  
CE/Z07

Scale @ A3  
NTS

Drawn  
SP

Checked

Approved

Project No.  
CS/079052

Date  
02/06/2015

BS1192 Compliant  
rev

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Capita Property and Infrastructure Ltd.

## Option 4C

Refurbishment of all areas to Zone 1, 2 and 3, including refurbishment to roof. Building wrap to Zones 3 and 4 and temporary roof to all zones.



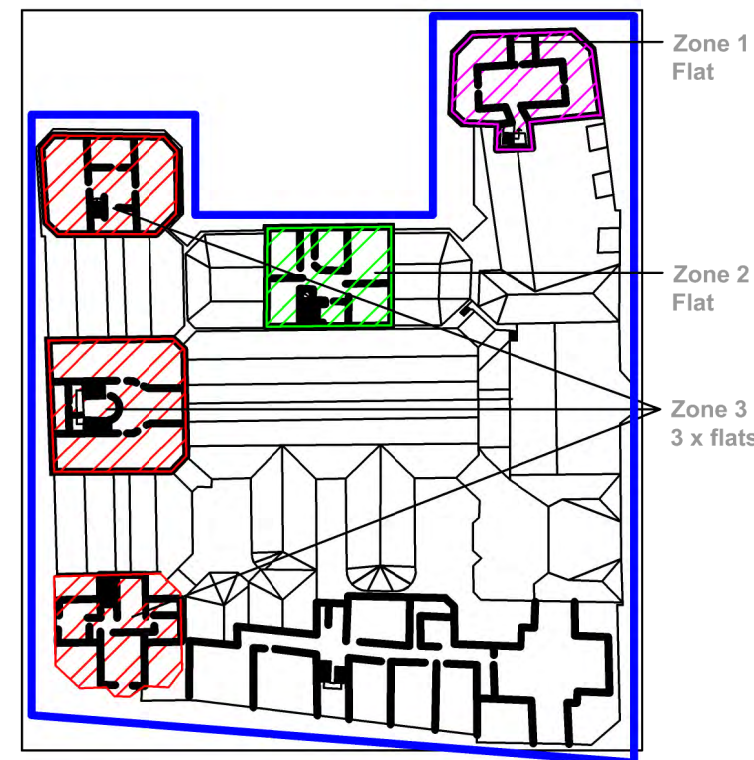
Ground Floor



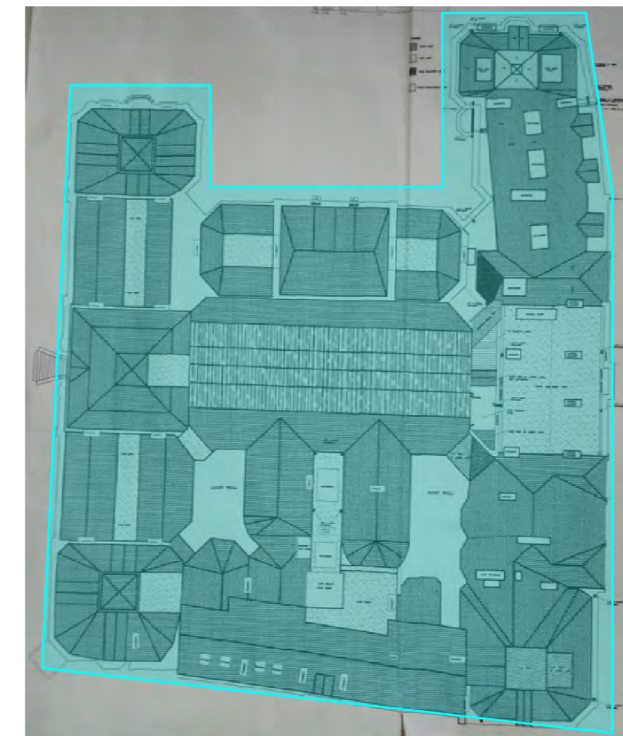
First Floor



Second Floor







Third Floor



Roof Plan

Temporary roof to all areas

### Key

-  Zone 1 - full refurbishment
-  Zone 2 - full refurbishment
-  Zone 3 - full refurbishment
-  Building wrap

### Costs

Zone 1	£778,211
Zone 2	£3,840,996
Zone 3	£6,184,685
Roof refurbishment to Zones 1, 2 & 3	£6,900,000
Temporary roof to all zones	£1,280,000
Facade retention	£750,000
Building wrap	£125,000
DDA compliance	£1,970,700
Other compliance requirements	£1,642,250
Allowance for basement	£1,000,000
<b>Cumulative Total</b>	<b>£24,471,842</b>

### Floor Areas

Floor Level	Zone 1	Zone 2	Zone 3
Ground	381m <sup>2</sup> / 4101 sq ft	1150m <sup>2</sup> / 12378 sq ft	744m <sup>2</sup> / 8008 sq ft
First	371m <sup>2</sup> / 3993 sq ft	782m <sup>2</sup> / 8417 sq ft	684m <sup>2</sup> / 7363 sq ft
Second	322m <sup>2</sup> / 3466 sq ft	1188m <sup>2</sup> / 12787 sq ft	684m <sup>2</sup> / 7363 sq ft
Third	100m <sup>2</sup> / 1076 sq ft	106m <sup>2</sup> / 1141 sq ft	353m <sup>2</sup> / 3799 sq ft
<b>Total</b>	<b>1174m<sup>2</sup> / 12636 sq ft</b>	<b>3226m<sup>2</sup> / 34723 sq ft</b>	<b>2465m<sup>2</sup> / 26533 sq ft</b>

Client  
Welsh Government

Project  
Coal Exchange Feasibility Study

Drawing  
Option 4C

Drawing no.  
CE/Z08

Scale @ A3  
NTS

Drawn  
SP

Checked  
SP

Approved

Project No.  
CS/079052

Date  
02/06/2015

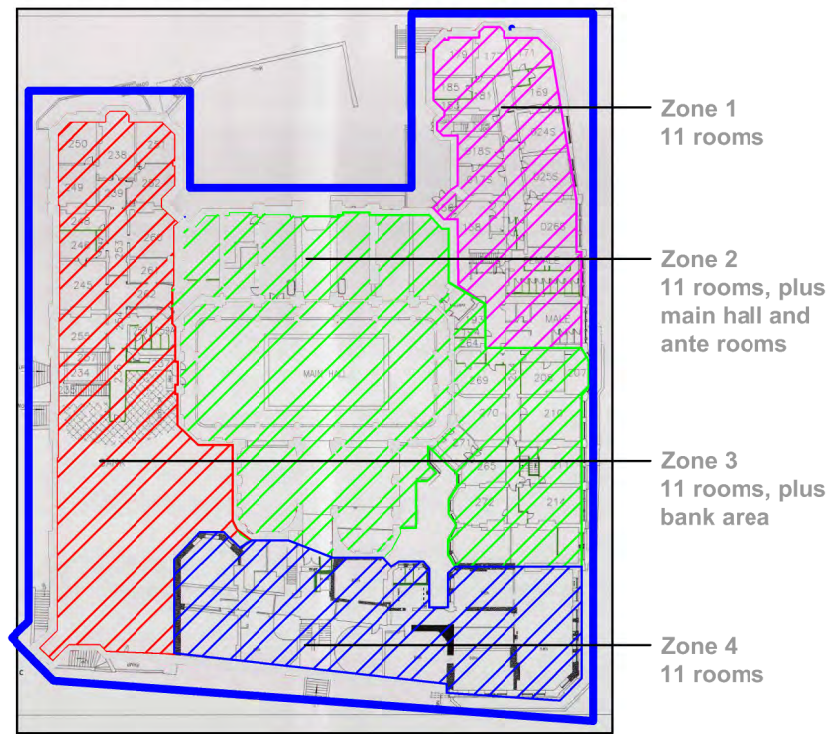
BS1192 Compliant  
rev

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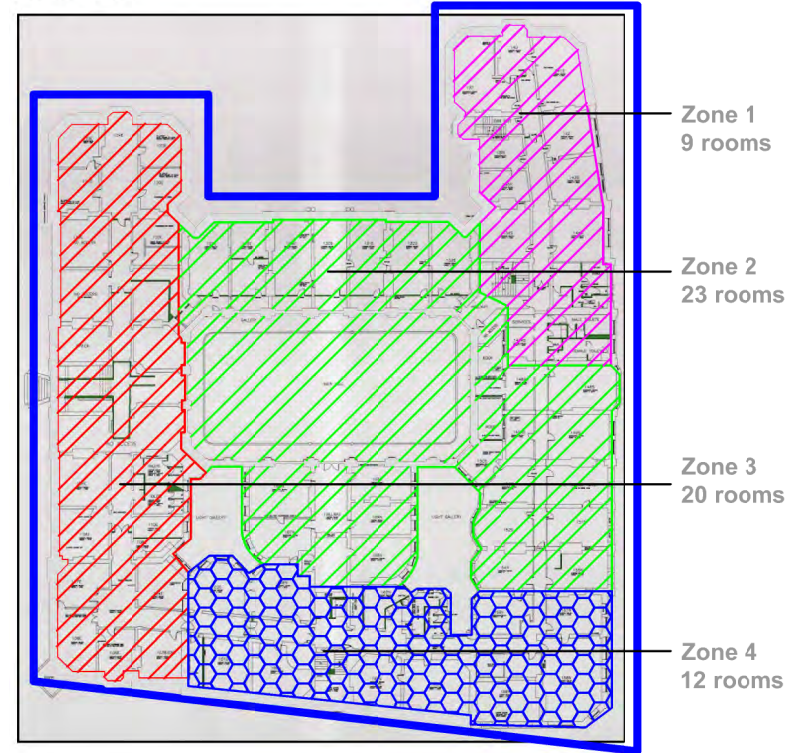
Ty Menter, Unit G1, Main Avenue, Treforest Industrial Estate,  
Treforest, CF37 5YL - 01443 823200  
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Capita Property and Infrastructure Ltd.

### Option 5A

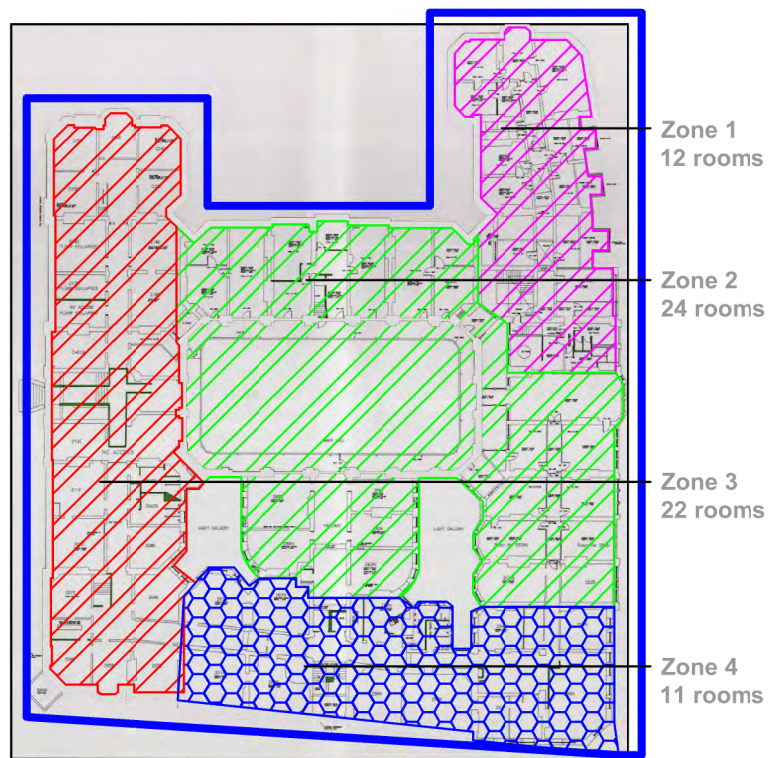
Refurbishment of all areas to Zone 1, Zone 2, Zone 3 ( as option 4C) and Zone 4 ground floor, with upper floors to Zone 4 structurally complete. Includes refurbishment of entire roof. Building wrap to building and temporary roof over all areas to undertake works.



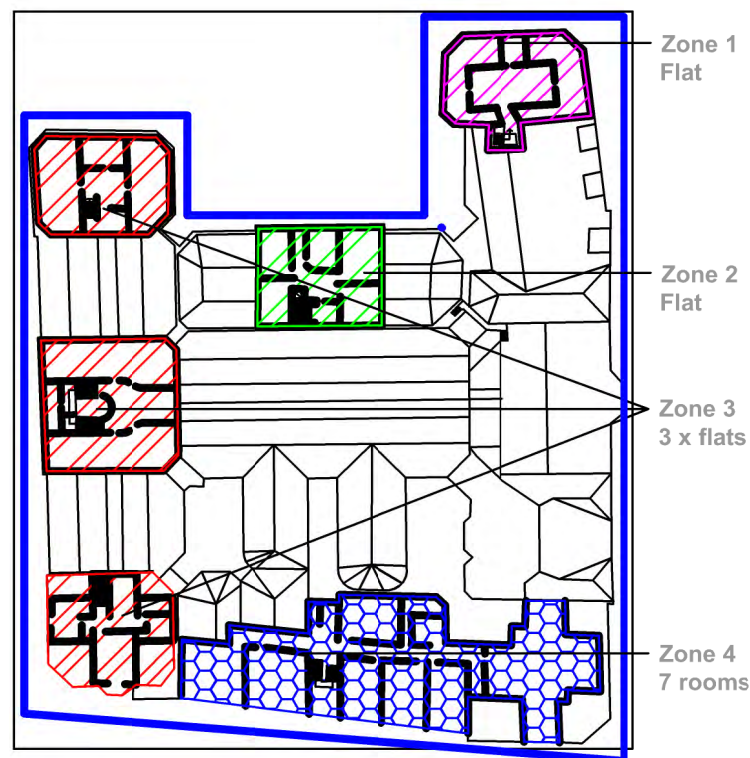
Ground Floor



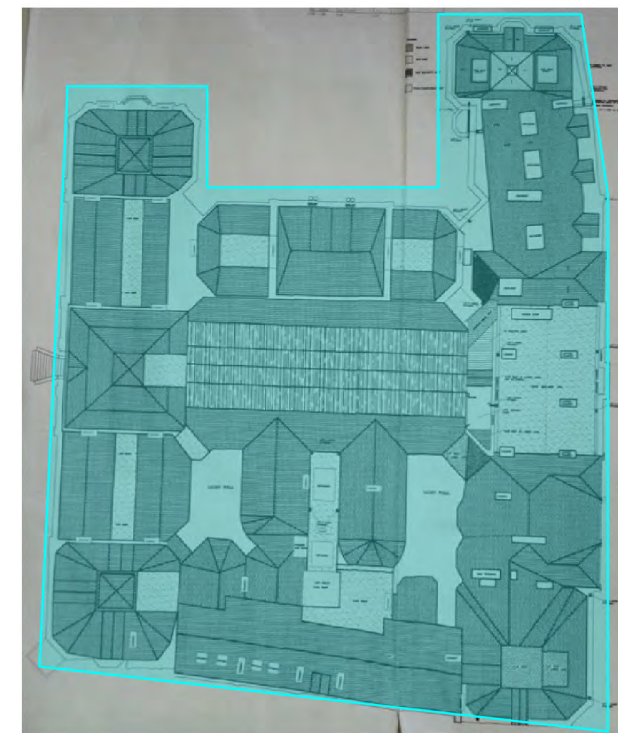
First Floor



Second Floor










Third Floor



Roof Plan

Temporary roof to all areas

### Key

-  Zone 1 - full refurbishment
-  Zone 2 - full refurbishment
-  Zone 3 - full refurbishment
-  Zone 3 - structurally complete
-  Zone 4 - full refurbishment
-  Zone 4 - structurally complete
-  Building wrap

### Costs

Zone 1	£778,211
Zone 2	£3,840,996
Zone 3	£6,184,685
Zone 4	£3,643,686
Roof refurbishment to all zones	£8,068,400
Temporary roof to all areas	£1,280,000
Facade retention	£750,000
Building wrap	£125,000
DDA compliance	£2,607,900
Other compliance requirements	£2,173,250
Allowance for basement	£1,000,000
<b>Cumulative Total</b>	<b>£30,452,128</b>

### Floor Areas

Floor Level	Zone 1	Zone 2	Zone 3	Zone 4
Ground	381m <sup>2</sup> / 4101 sq ft	1150m <sup>2</sup> / 12378 sq ft	744m <sup>2</sup> / 8008 sq ft	508m <sup>2</sup> / 5468 sq ft
First	371m <sup>2</sup> / 3993 sq ft	782m <sup>2</sup> / 8417 sq ft	684m <sup>2</sup> / 7363 sq ft	522m <sup>2</sup> / 5619 sq ft
Second	322m <sup>2</sup> / 3466 sq ft	1188m <sup>2</sup> / 12787 sq ft	684m <sup>2</sup> / 7363 sq ft	504m <sup>2</sup> / 5425 sq ft
Third	100m <sup>2</sup> / 1076 sq ft	106m <sup>2</sup> / 1141 sq ft	353m <sup>2</sup> / 3799 sq ft	327m <sup>2</sup> / 3519 sq ft
<b>Total</b>	<b>1174m<sup>2</sup> / 12636 sq ft</b>	<b>3226m<sup>2</sup> / 34723 sq ft</b>	<b>2465m<sup>2</sup> / 26533 sq ft</b>	<b>1861m<sup>2</sup> / 20031 sq ft</b>

Client  
Welsh Government

Project  
Coal Exchange Feasibility Study

Drawing  
Option 5A

Drawing no.  
CE/Z09

Scale @ A3  
NTS

Drawn  
SP

Checked  
SP

Approved

Project No.  
CS/079052

Date  
02/06/2015

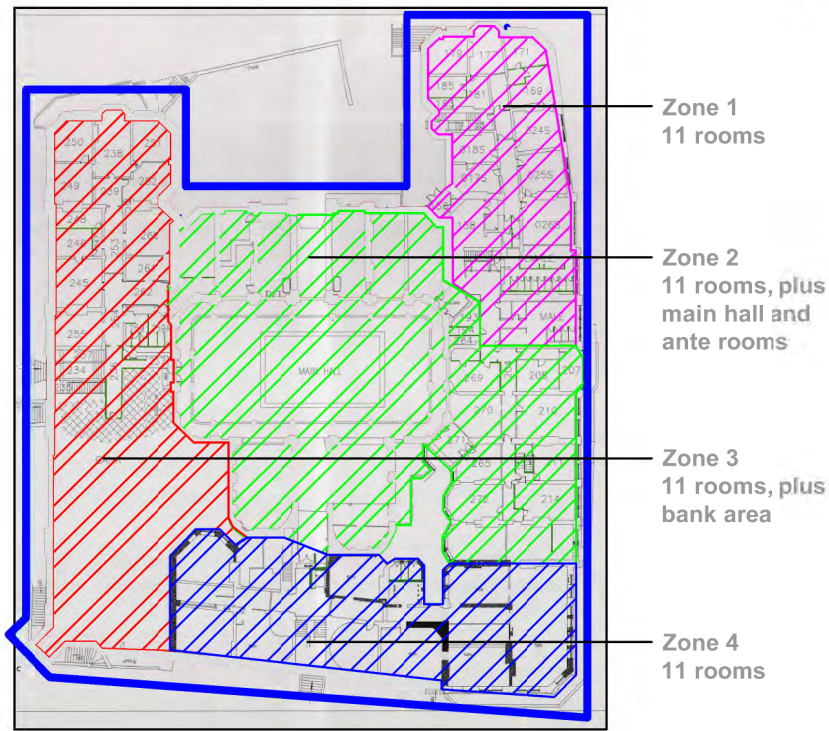
BS1192 Compliant  
rev

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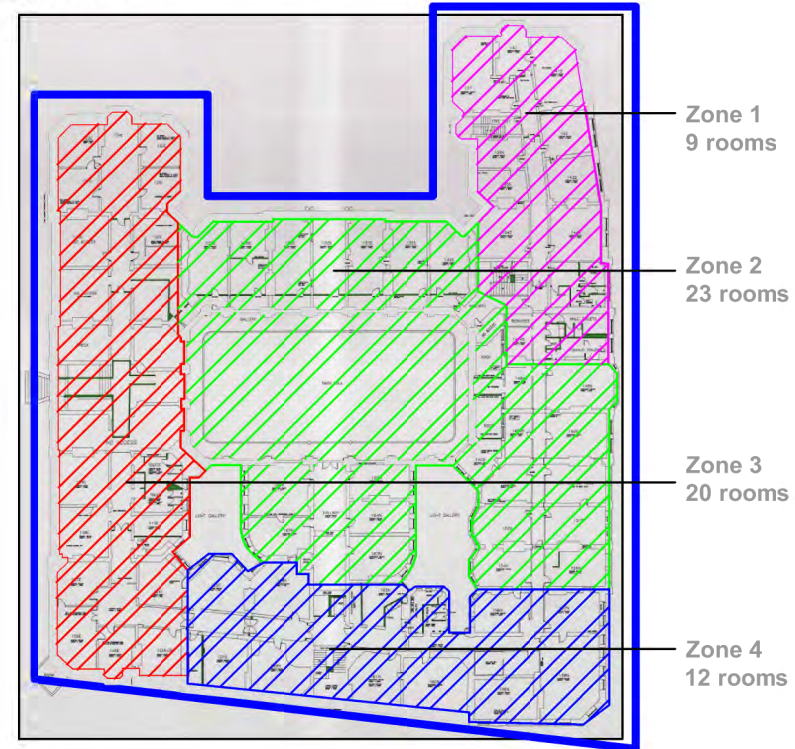
Ty Menter, Unit G1, Main Avenue, Treforest Industrial Estate,  
Treforest, CF37 5YL - 01443 823200  
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Capita Property and Infrastructure Ltd.

## Option 5B

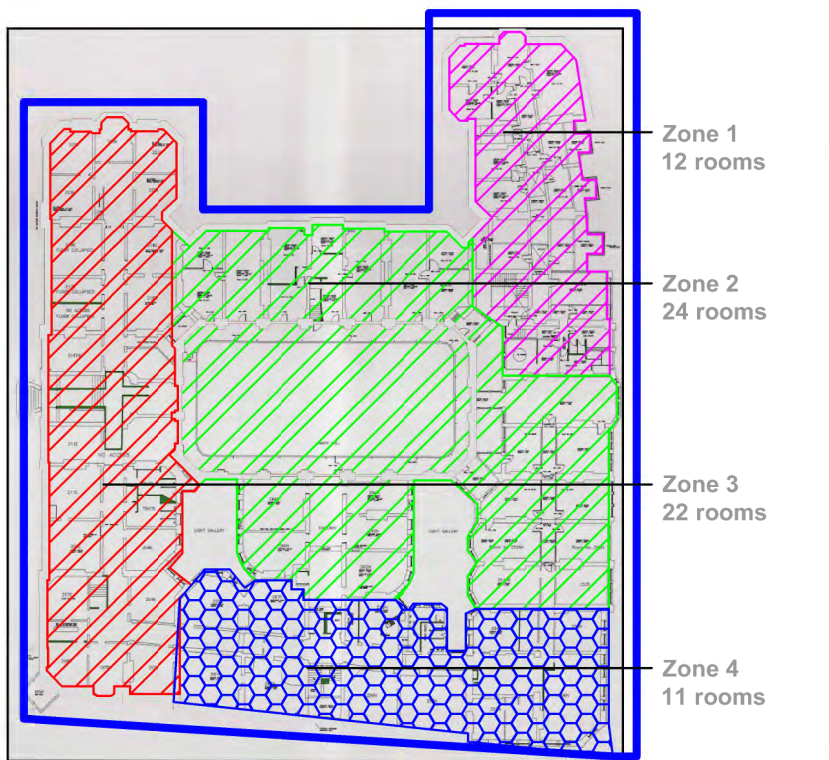
Refurbishment of all areas to Zone 1, Zone 2, Zone 3 (as option 4C) and Zone 4 ground floor and first floor, with upper floors to Zone 4 structurally complete. Includes refurbishment of entire roof. Building wrap to building and temporary roof over all areas to undertake works.



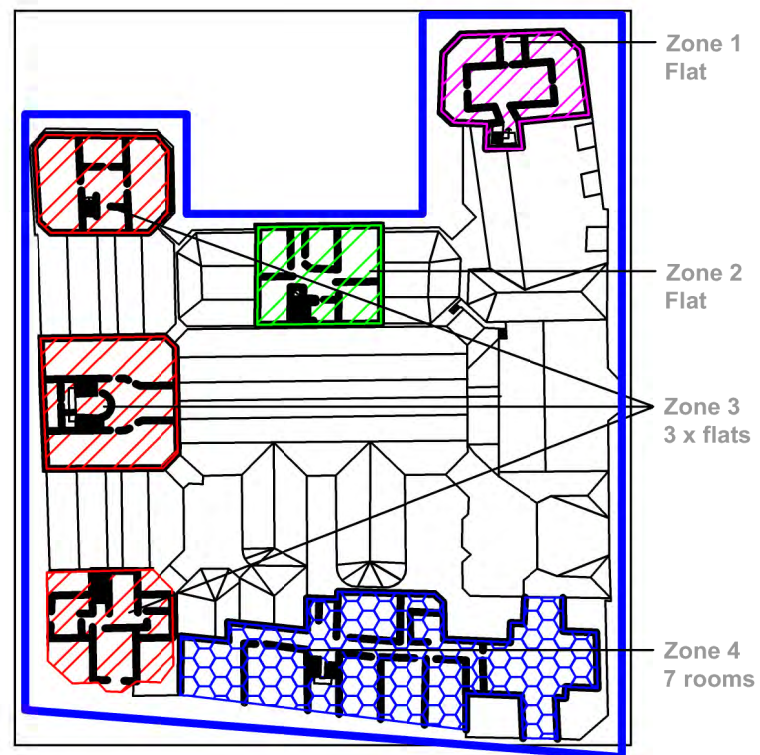
Ground Floor



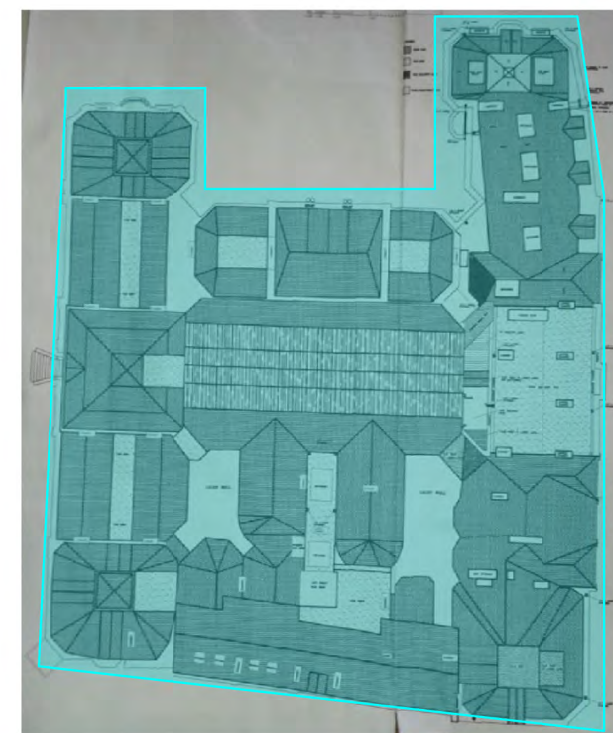
First Floor



Second Floor



Third Floor



Roof Plan

Temporary roof to all areas








### Costs

Zone 1	£778,211
Zone 2	£3,840,996
Zone 3	£6,184,685
Zone 4	£4,118,329
Roof refurbishment to all zones	£8,068,400
Temporary roof to all areas	£1,280,000
Facade retention	£750,000
Building wrap	£125,000
DDA compliance	£2,607,900
Other compliance requirements	£2,173,250
Allowance for basement	£1,000,000
<b>Cumulative Total</b>	<b>£30,926,771</b>

### Floor Areas

Floor Level	Zone 1	Zone 2	Zone 3	Zone 4
Ground	381m <sup>2</sup> / 4101 sq ft	1150m <sup>2</sup> / 12378 sq ft	744m <sup>2</sup> / 8008 sq ft	508m <sup>2</sup> / 5468 sq ft
First	371m <sup>2</sup> / 3993 sq ft	782m <sup>2</sup> / 8417 sq ft	684m <sup>2</sup> / 7363 sq ft	522m <sup>2</sup> / 5619 sq ft
Second	322m <sup>2</sup> / 3466 sq ft	1188m <sup>2</sup> / 12787 sq ft	684m <sup>2</sup> / 7363 sq ft	504m <sup>2</sup> / 5425 sq ft
Third	100m <sup>2</sup> / 1076 sq ft	106m <sup>2</sup> / 1141 sq ft	353m <sup>2</sup> / 3799 sq ft	327m <sup>2</sup> / 3519 sq ft
<b>Total</b>	<b>1174m<sup>2</sup> / 12636 sq ft</b>	<b>3226m<sup>2</sup> / 34723 sq ft</b>	<b>2465m<sup>2</sup> / 26533 sq ft</b>	<b>1861m<sup>2</sup> / 20031 sq ft</b>

### Key

-  Zone 1 - full refurbishment
-  Zone 2 - full refurbishment
-  Zone 3 - full refurbishment
-  Zone 3 - structurally complete
-  Zone 4 - full refurbishment
-  Zone 4 - structurally complete
-  Building wrap

Client  
Welsh Government

Project  
Coal Exchange Feasibility Study

Drawing  
Option 5B

Drawing no.  
CE/Z10

Scale @ A3  
NTS

Drawn  
SP

Checked  
SP

Approved

Project No.  
CS/079052

Date  
02/06/2015

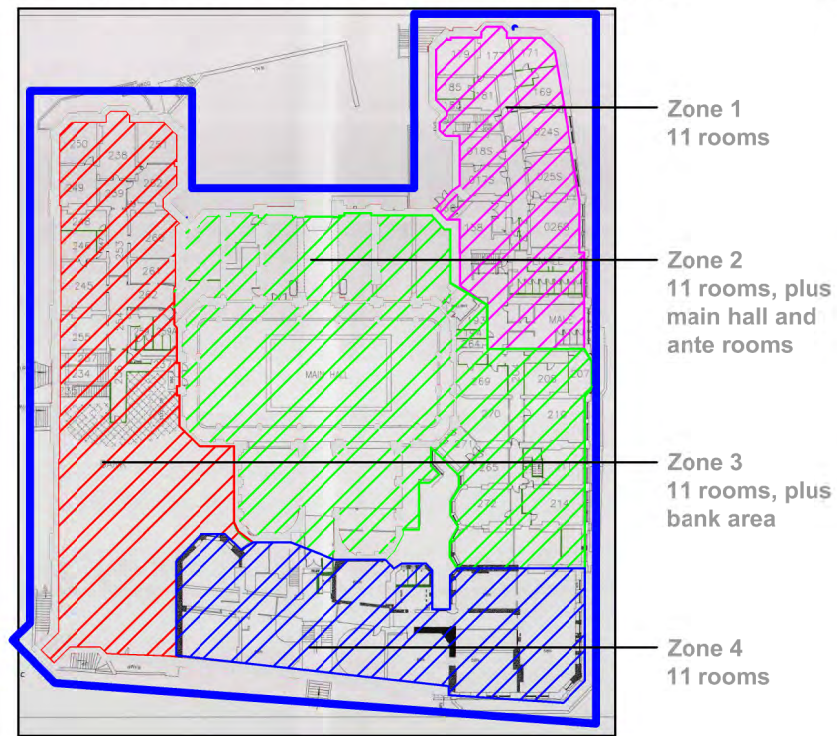
BS1192 Compliant  
rev

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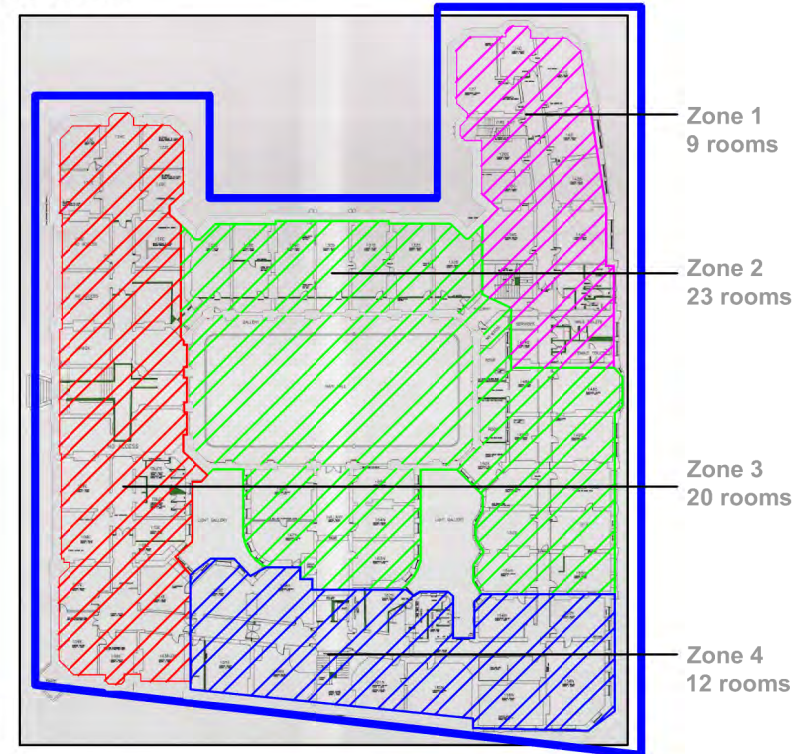
Ty Menter, Unit G1, Main Avenue, Treforest Industrial Estate,  
Treforest, CF37 5YL - 01443 823200  
www.capitaproperty.co.uk  
Capita Property and Infrastructure Ltd.

## Option 5C

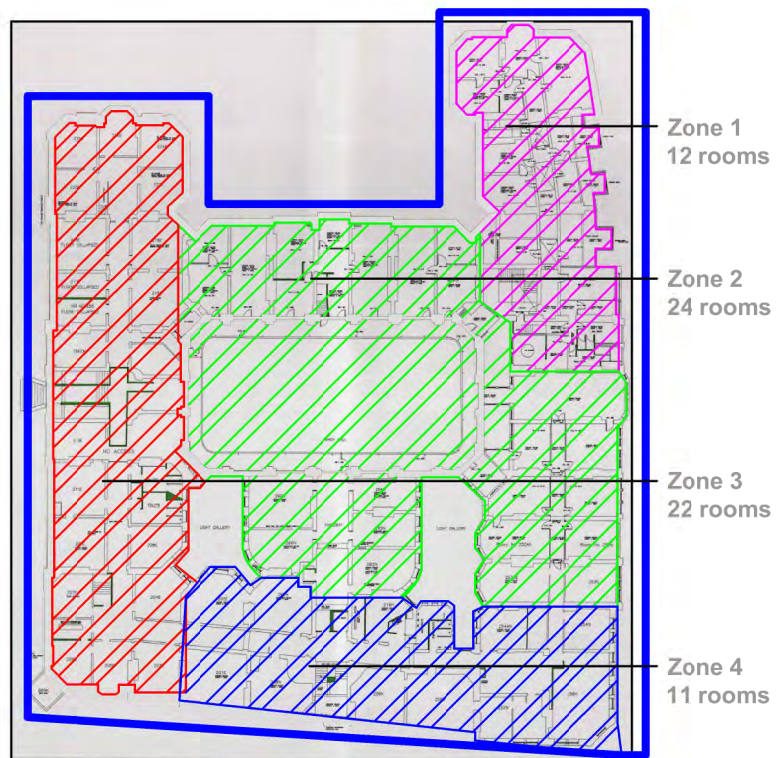
Refurbishment of all areas to Zone 1, Zone 2, Zone 3 and Zone 4, including refurbishment of entire roof.  
Building wrap to building and temporary roof over all areas to undertake works.



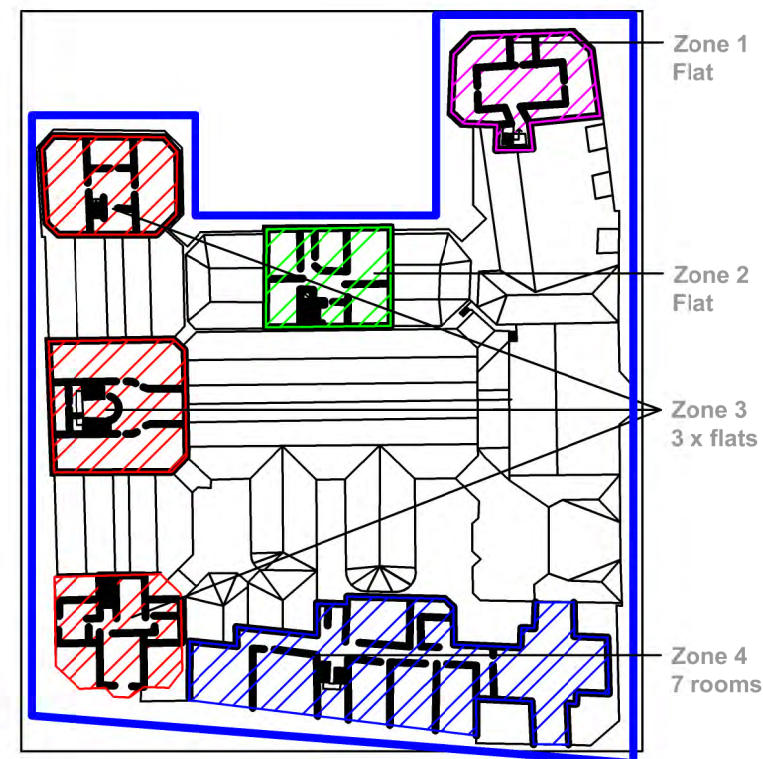
Ground Floor



First Floor



Second Floor



Third Floor







### Costs

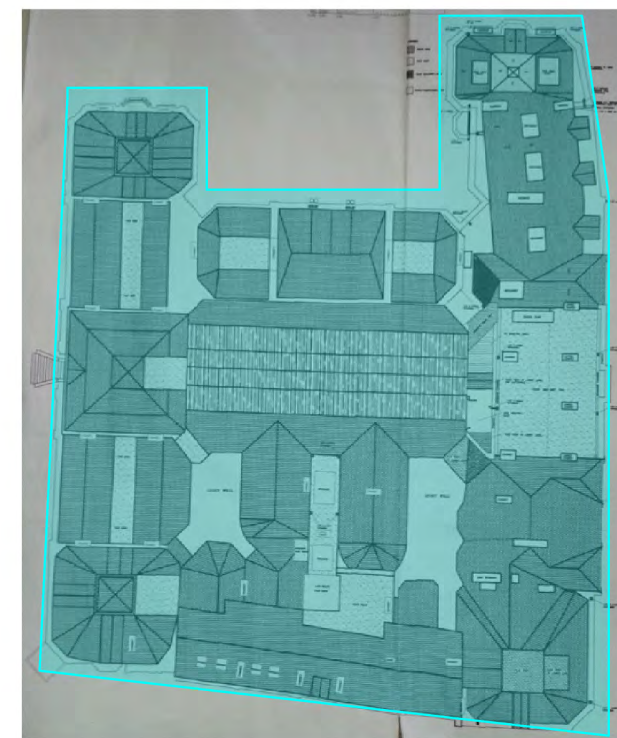
Zone 1	£778,211
Zone 2	£3,840,996
Zone 3	£6,184,685
Zone 4	£5,072,094
Roof refurbishment to all zones	£8,068,400
Temporary roof to all areas	£1,280,000
Facade retention	£750,000
Building wrap	£125,000
DDA compliance	£2,610,900
Other compliance requirements	£2,175,750
Allowance for basement	£1,000,000
<b>Cumulative Total</b>	<b>£31,886,036</b>

### Floor Areas

Floor Level	Zone 1	Zone 2	Zone 3	Zone 4
Ground	381m <sup>2</sup> / 4101 sq ft	1150m <sup>2</sup> / 12378 sq ft	744m <sup>2</sup> / 8008 sq ft	508m <sup>2</sup> / 5468 sq ft
First	371m <sup>2</sup> / 3993 sq ft	782m <sup>2</sup> / 8417 sq ft	684m <sup>2</sup> / 7363 sq ft	522m <sup>2</sup> / 5619 sq ft
Second	322m <sup>2</sup> / 3466 sq ft	1188m <sup>2</sup> / 12787 sq ft	684m <sup>2</sup> / 7363 sq ft	504m <sup>2</sup> / 5425 sq ft
Third	100m <sup>2</sup> / 1076 sq ft	106m <sup>2</sup> / 1141 sq ft	353m <sup>2</sup> / 3799 sq ft	327m <sup>2</sup> / 3519 sq ft
<b>Total</b>	<b>1174m<sup>2</sup> / 12636sq ft</b>	<b>3226m<sup>2</sup> / 34723 sq ft</b>	<b>2465m<sup>2</sup> / 26533 sq ft</b>	<b>1861m<sup>2</sup> / 20031 sq ft</b>

### Key

-  Zone 1 - full refurbishment
-  Zone 2 - full refurbishment
-  Zone 3 - full refurbishment
-  Zone 3 - structurally complete
-  Zone 4 - full refurbishment
-  Building wrap



Roof Plan

Temporary roof to all areas

Client  
Welsh Government

Project  
Coal Exchange Feasibility Study

Drawing  
Option 5C

Drawing no.  
CE/Z11

Scale @ A3  
NTS

Drawn  
SP

Checked  
SP

Approved

Project No.  
CS/079052

Date  
02/06/2015

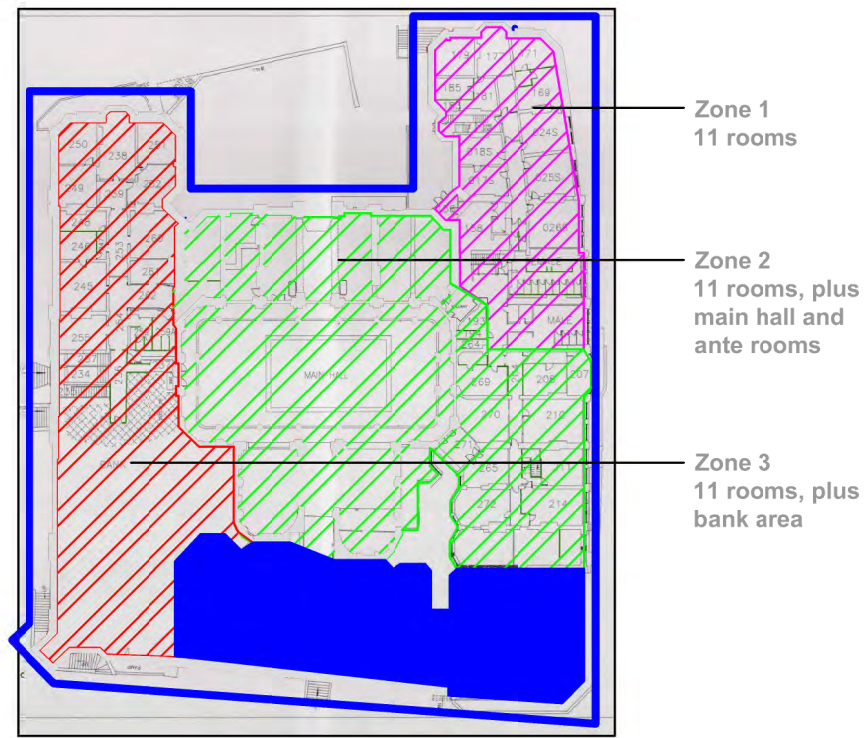
BS1192 Compliant  
rev

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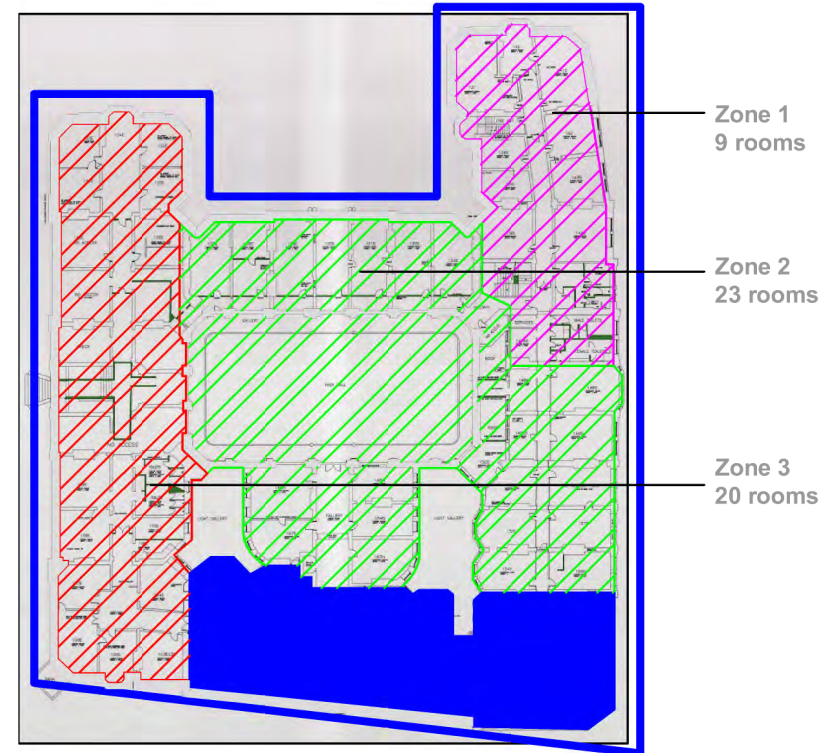
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Capita Property and Infrastructure Ltd.

## Option 5D

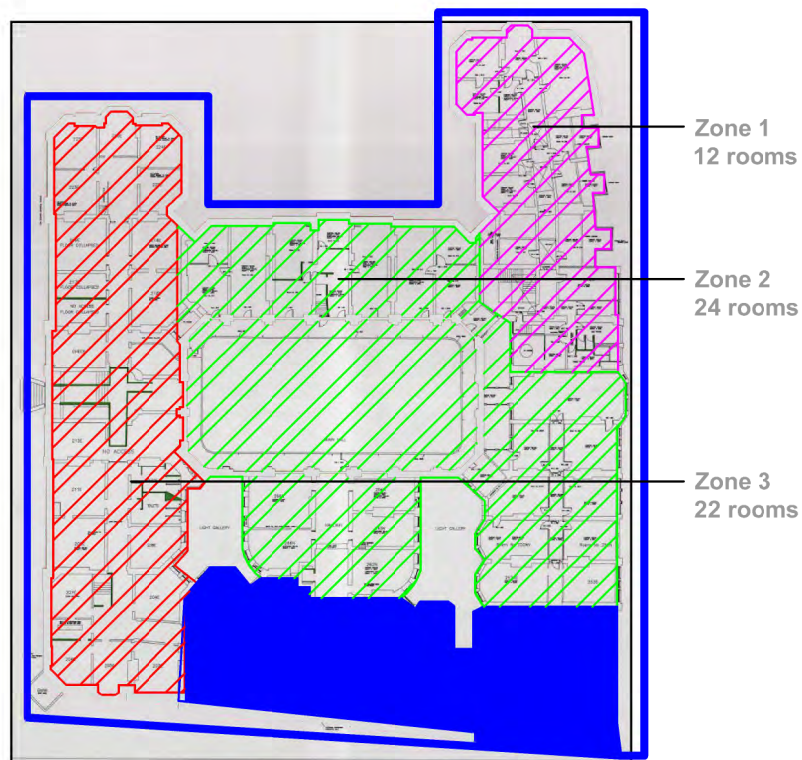
Refurbishment of all areas to Zone 1, Zone 2, and Zone 3. Demolition of Zone 4.  
 Building wrap to building and temporary roof over all areas to undertake works.



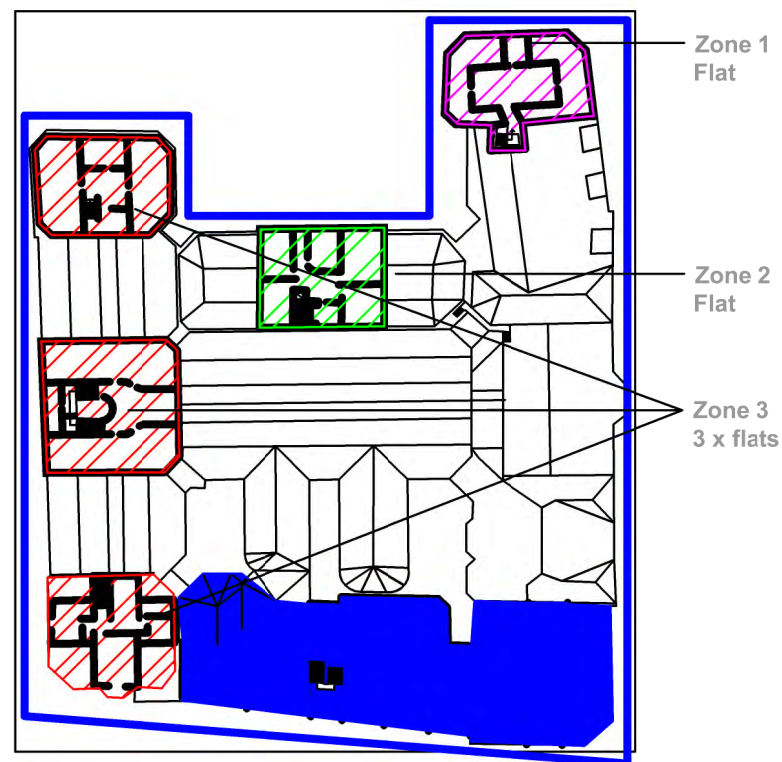
Ground Floor



First Floor



Second Floor



Third Floor

### Costs

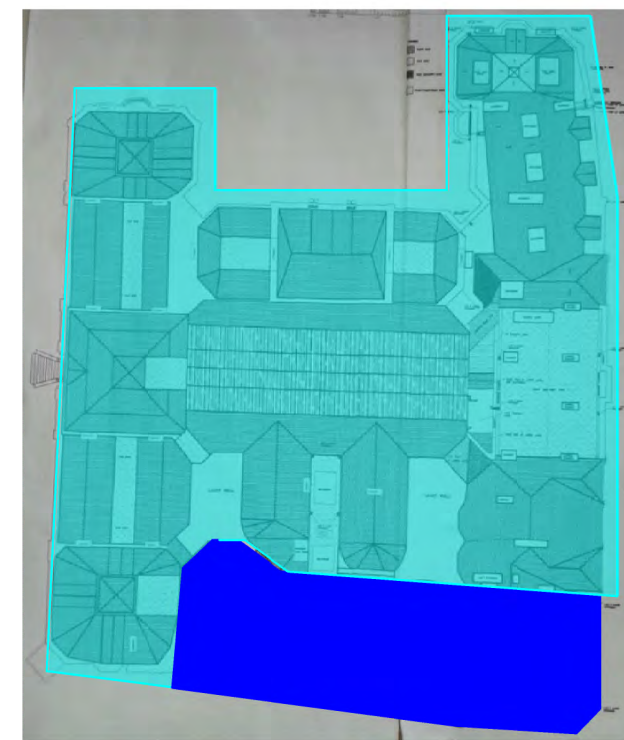
Zone 1	£778,211
Zone 2	£3,840,996
Zone 3	£6,184,685
Zone 4 - demolition	£1,875,000
Roof refurbishment to zones 1, 2 & 3	£6,900,000
Temporary roof to all areas	£1,000,000
Facade retention	£600,000
Building wrap	£125,000
DDA compliance	£1,970,700
Other compliance requirements	£1,642,250
Allowance for basement	£800,000
<b>Cumulative Total</b>	<b>£25,716,842</b>

### Key

- Zone 1 - full refurbishment
- Zone 2 - full refurbishment
- Zone 3 - full refurbishment
- Zone 3 - structurally complete
- Zone 4 - demolition
- Building wrap

### Floor Areas

Floor Level	Zone 1	Zone 2	Zone 3	Zone 4
Ground	381m <sup>2</sup> / 4101 sq ft	1150m <sup>2</sup> / 12378 sq ft	744m <sup>2</sup> / 8008 sq ft	508m <sup>2</sup> / 5468 sq ft
First	371m <sup>2</sup> / 3993 sq ft	782m <sup>2</sup> / 8417 sq ft	684m <sup>2</sup> / 7363 sq ft	522m <sup>2</sup> / 5619 sq ft
Second	322m <sup>2</sup> / 3466 sq ft	1188m <sup>2</sup> / 12787 sq ft	684m <sup>2</sup> / 7363 sq ft	504m <sup>2</sup> / 5425 sq ft
Third	100m <sup>2</sup> / 1076 sq ft	106m <sup>2</sup> / 1141 sq ft	353m <sup>2</sup> / 3799 sq ft	327m <sup>2</sup> / 3519 sq ft
<b>Total</b>	<b>1174m<sup>2</sup> / 12636 sq ft</b>	<b>3226m<sup>2</sup> / 34723 sq ft</b>	<b>2465m<sup>2</sup> / 26533 sq ft</b>	<b>1861m<sup>2</sup> / 20031 sq ft</b>



Roof Plan

Temporary roof to Zones 1, 2 and 3

Client  
Welsh Government

Project  
Coal Exchange Feasibility Study

Drawing  
Option 5D

Drawing no.  
CE/Z12

Scale @ A3  
NTS

Drawn  
SP

Checked  
SP

Approved

Project No.  
CS/079052

Date  
02/06/2015

BS1192 Compliant  
rev

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Building Consultancy

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Treforest, CF37 5YL - 01443 823200  
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## Appendix C

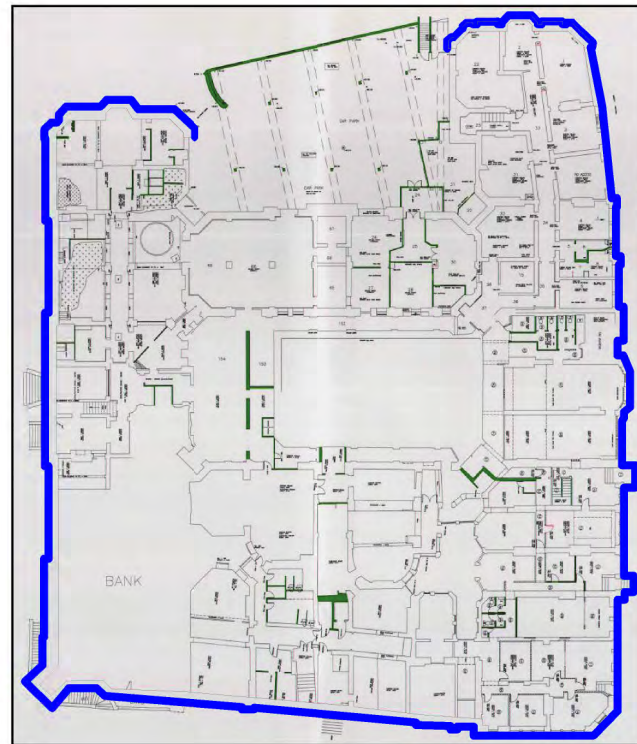
### Areas retaining high levels of original fabric

Pack Page 123

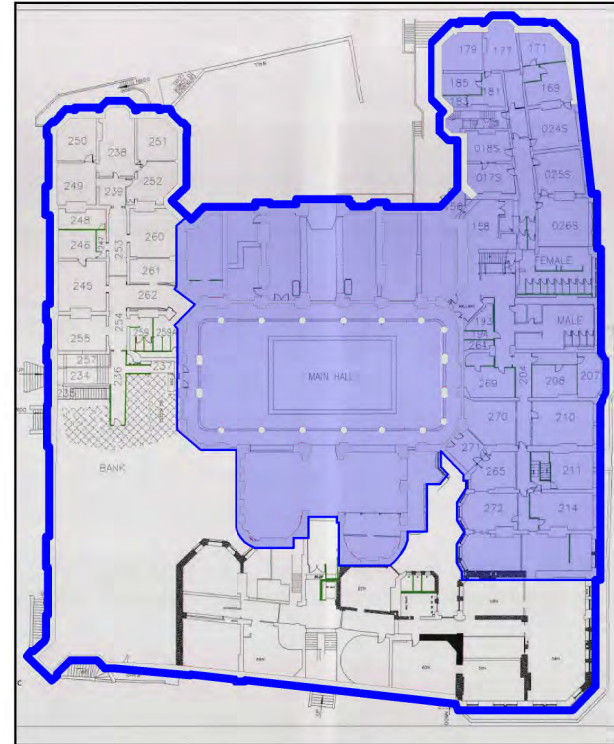
**Areas where most original fabric and character survive**

1. Exchange Hall including foyer, hall and ante rooms. Exchange hall includes balcony galleries and original roof.
2. All facades.
3. South entrance courtyard (though partially obliterated by car park).
4. Roof features including cupolas, turrets and general massing.

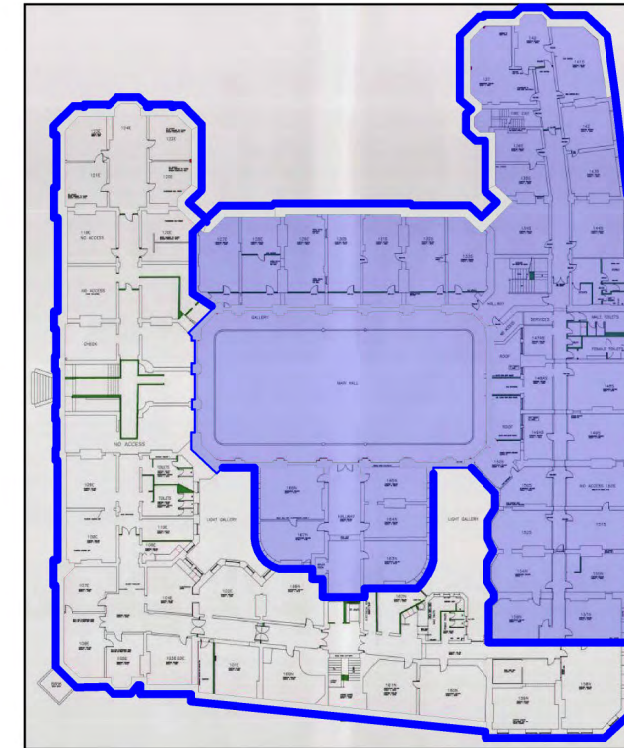
 Areas where most original fabric and character survive



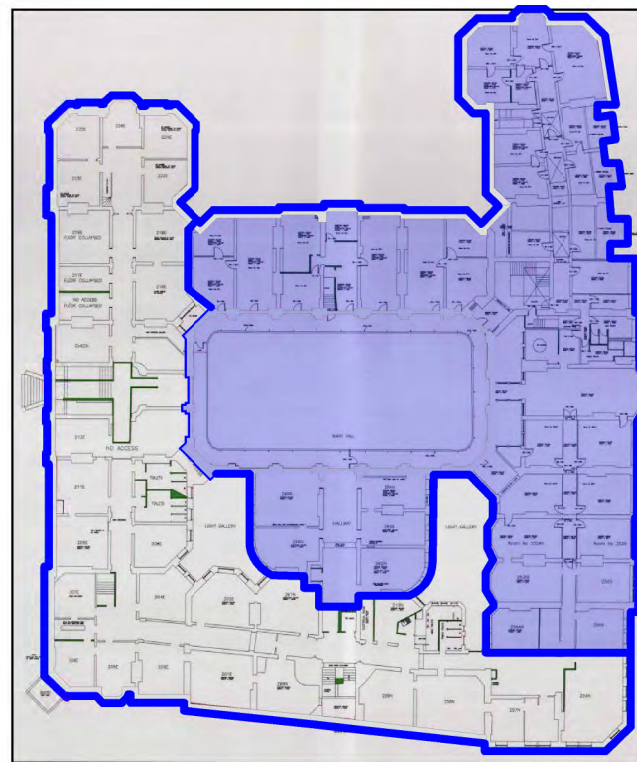
Basement



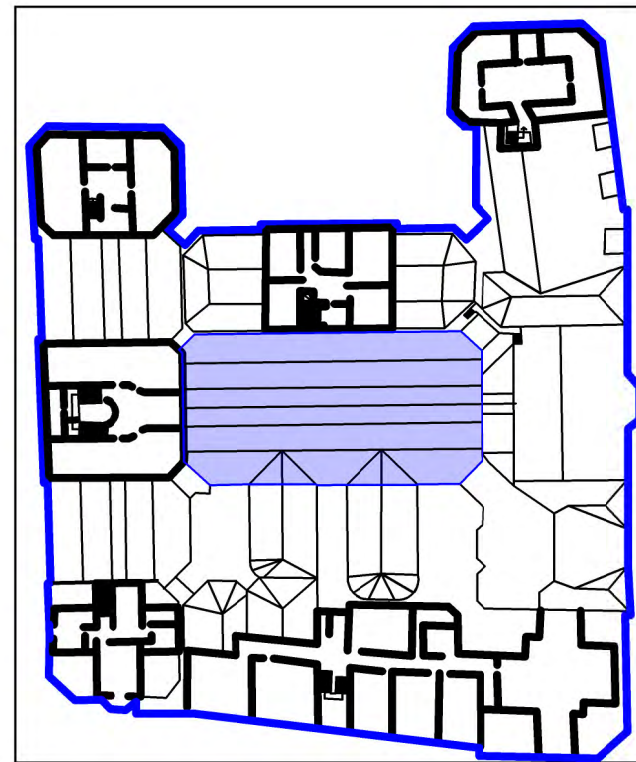
Ground Floor



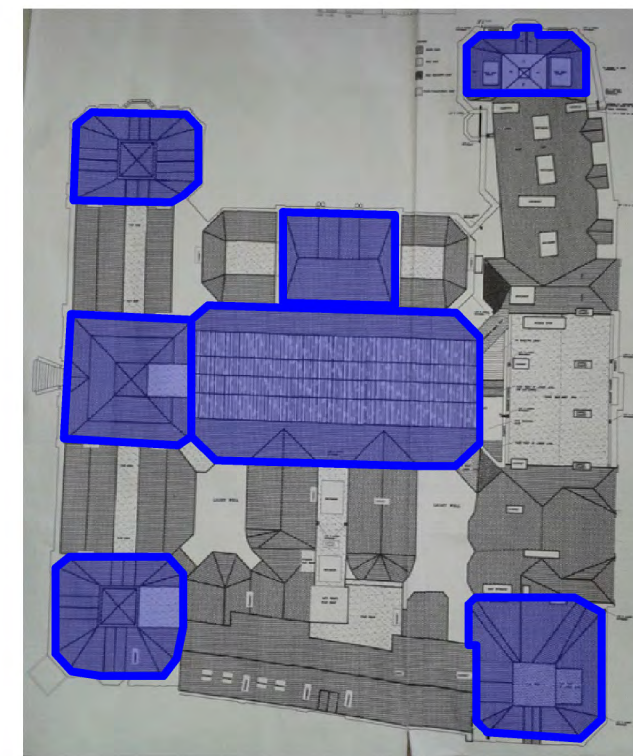
First Floor



Second Floor



Third Floor



Roof Plan

Client			
Welsh Government			
Project			
Coal Exchange Feasibility Study			
Drawing		Drawing no.	
Areas retaining high levels of original fabric		CE/H01	
Scale @ A3	Drawn	Checked	Approved
NTS	SP		
Project No.		Date	
CS/079052		02/06/2015	
BS1192 Compliant rev			

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## Appendix D

### Historic Wales Report 14015

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## Historic Wales Report

Dataset	Cadw Listed Buildings
Title	Cardiff Exchange Building
Type	Listed Building
Dataset UID	14015
Community	Butetown

**Location**  
Prominently sited occupying the whole of the central area of the square.

Date Listed 5/19/1975  
Last Amendment 8/21/1998  
Grade II\*

**History**  
Built 1884-86 to design of Seward & Thomas, architects, on site of central gardens of Mount Stuart Square. Interior alterations to Exchange Hall by same architects 1911-12. Interior altered in 1970's including insertion of false ceiling in Exchange Hall. Underground car park added in late 1970's, disfiguring main entrance court.

**Reason for Listing**  
Graded II\* as one of most historically important commercial buildings in Wales, illustrating region's immense commercial power in late C19 and early C20.  
Group value.

**History**  
The Inner Harbour - An Historical Appraisal. An unpublished report prepared by The Survey of Cardiff for Cardiff Bay Development Corporation, 1989, p. 89-90.  
The Builder, February 13, 1886.  
S Williams, Cardiff Yesterday, Vol VI, 1983, Illus 30-32.

**Interior**  
Retains entrance hall with Jacobethan style moulded plaster ceiling, panelled walls, and woodblock and inlay floor. Two fireplaces to R with C17 style wooden surrounds. At rear against wood and glass partition wall, two lions on high plinths supporting clock faces showing times of Cardiff high tides. Further rooms to L and R. Doors in rear partition wall lead to central Coal and Shipping Hall with exchange floor surrounded by galleried tiers of offices, in Jacobethan style dark wood. Inserted coved ceiling has reduced height to 2 storeys, hiding centrally glazed roof, with arched ribs and top tier of offices which remain as corridor. Fascia of top gallery remains visible with cornice, and swags and garlands, supported by Corinthian columns with gilded capitals and in lower zones carved decoration, dolphins alternating with trophies of pick, a shovel and miner's lamp. Columns paired at central bays of short sides of hall, framing to E barometer, and to W segmental pedimented aedicule with clock flanked by dragons, and inscription 'Tempus Fugit'. Gallery Fascia at this level with panelling and aprons. Gallery supported on brackets with alternating corbels of dragon and lion heads. Decorated plaster panels on beneath overhanging balconies. Sunk central floor, surrounded by wooden partitions to offices. Deeper area to rear (N) with fireplace, wood and glass partitioning, and lit by stained glass windows including

stylised ships and inscription 'Ye Olde Order Changeth'.

**Exterior**  
Pale cream limestone (Corsham stone) on snecked grey stone plinth. Yellow brick on W elevation. Slate roofs, and chimneys mainly in yellow brick.

Style derived from French Renaissance models. Main entrance front faces S. Three storeys and basement plus attic storeys in central pedimented 'frontispiece', with hipped pavilion roof. Attic pediment over round window. Parapet has windows with segmental pediments. Lower attic storey with central semi-circular architrave enclosing window group, flanked by windows with moulded architraves. Lower pediment on paired engaged fluted Corinthian columns. Floral relief in triangular pediment surmounted by Royal Arms. Second floor windows have horned architraves with swags, first floor windows generally round-headed, ground floor windows paired beneath broken scroll pediments.

Two asymmetrical projecting wings (pavilion-type roofs) enclose forecourt with added underground carpark in concrete with cast concrete balusters. Wing elevations to forecourt treated in similar fashion to main front, but W wing has extra bays. Polygonal S returns of wings with splayed bay windows on all floors, flanked by external chimneys with stone panelling and pilasters.

Curvilinear pavilion-type roofs to E range. End and centre bays of elevation articulated by pilasters. Centre bay shallow 'frontispiece' with extra attic storeys, close in style to main front. End bays with pedimented attic windows. Grey stone basement with segmental-headed windows. At NE corner, steps up to projecting porch to Barclays Bank, resident here since building opened.

To N, central advanced block of four storeys, five bays, with flanking asymmetrical three storey blocks having pedimented attic windows. To W, less ambitious treatment in yellow brick with bathstone dressings, three storeys, but bays behind wing of entrance front two storeys with dormers in attic.

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## Appendix E

### Example Building Wraps

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## Appendix F Sources of Material

## **Sources of Material**

- Structural Inspection of The Exchange Building; Curtains Consulting Engineers Plc (1994)
- Inspection of Condition (Revision 2 and 3); RVW Consulting (2013)
- Condition Survey interim report; RVW Consulting (2013)
- Explanation and clarification of emergency works; RVW Consulting (2013)
- Schedule of immediate works to dangerous structure; RVW Consulting (2013)
- Risk Assessment of the Coal Exchange; RVW Consulting, Safety Consultant, Willmott Dixon and H Smith (2013)
- Design Statement for Planning Submission; Aukett Fitzroy Robinson (2006)
- Listed Architectural Fabric Appraisal (draft copy); Aukett Fitzroy Robinson (2005)

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Capita Property and Infrastructure,  
Unit G1, Ty Menter  
The Willowford,  
Treforest Industrial Estate,  
Treforest,  
Pontypridd  
CF37 5BF

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**P-04-539 Save Cardiff Coal Exchange – Correspondence from Save the Coal Exchange to Bethan Jenkins AM, 18.08.15**

**From:** Ian Hill  
**Sent:** 18 August 2015 15:38  
**To:** Jenkins, Bethan (Assembly Member)  
**Subject:** The Coal Exchange

Hi Bethan,

I have just received the following from Jon Avent of Mann Williams, after Save The Coal Exchange commissioned a structural survey of the hall and foyer of the Exchange. The full report will be with us in about 10 days.

"We are satisfied that the roof structure is currently stable and does not pose a safety risk to persons within the hall.

There are a very small number of cracked panes of glass noted (3), but the fractures are long standing and the units are wired glazing so there is no adverse risk to safety.

It is noted that there is currently missing ceiling tiles at the east end of the hall, and these should be replaced.

There is evidence of some ongoing water ingress, and this is causing some damage to finishes, rather than causing any significant structural safety concern.

In a similar manner to the front elevation we will be recommending that an appropriate management regime is put in place to review on a monthly basis to ensure that there is no adverse progression of deterioration. We will be happy to do this at the same time as our monthly inspection of the south/entrance elevations.

In conclusion we are happy for persons to enter the main hall following replacement of loose/missing ceiling tiles."

**Mann Williams**

Consulting Civil & Structural Engineers  
Best Wishes  
Ian Hill

Edwina Hart MBE CStJ AC / AM  
Gweinidog yr Economi, Gwyddoniaeth a Thrafnidiaeth  
Minister for Economy, Science and Transport



Llywodraeth Cymru  
Welsh Government

Eich cyf/Your ref P-04-539  
Ein cyf/Our ref EH/03485/15

William Powell AM  
Chair - Petitions Committee

committeebusiness@Wales.gsi.gov.uk

07 September 2015

Dear William,

Thank you for your letter of 6 August regarding Cardiff Coal Exchange.

Officials from my Department, including Cadw, have been fully engaged in the work done to date in completing this initial stage of research and should any further, more detailed work be needed then this would be similarly carried out on a collaborative basis.

With regard to the initial feasibility study itself, a copy of the final version was sent to you on 14 August which I trust you have safely received.

Following further consideration of the initial feasibility work, I hope to write to you again on suggested next steps.

*Edwina Hart*

## **P-04-544 Ban the Shooting of Greenland White-fronted Geese**

### **Petition wording:**

We call on the National Assembly for Wales to urge the Welsh Government to reverse their decision not to ban the shooting of an endangered species, the Greenland White-fronted goose, meaning that Wales remains the only country on the flight path of this endangered species where they can still be legally shot and killed. Scientific evidence has shown that the species is extremely vulnerable to hunting pressures. In their consultation report, the Welsh Government also admit that failure to take appropriate steps to reduce as far as possible Greenland White-fronted geese adult mortality could be seen as a failure to meet conservation obligations. Unlike Scotland, Ireland, Iceland and Greenland there is no current ban on the shooting and killing of this endangered bird in Wales. A voluntary ban is in place on part of the Dyfi estuary in Wales but there is evidence that the geese also use other areas away from the estuary in mid and North Wales where no voluntary agreements are in place.

The population of these geese, as a whole, is declining and they have been of conservation concern since the late 1970s when sharp declines triggered protection from hunting on their wintering grounds. They receive heavy statutory protection. However, since the mid 1990s the population has again declined sharply. While WOS has acknowledged that long running voluntary bans on shooting are in place at some wetlands such as the Dyfi Estuary, it believes that nothing less than a statutory ban on shooting will ensure its protection. The society is concerned that any voluntary ban could be lifted at any time and that the current approach does not cover all the sites where this declining subspecies spends the winter.

**Petition raised by:** Aaron Davies

**Date Petition first considered by Committee:** 29 April 2014

**Number of signatures: 240**

Carl Sargeant AC / AM  
Y Gweinidog Cyfoeth Naturiol  
Minister for Natural Resources



Llywodraeth Cymru  
Welsh Government

Eich cyf/Your ref P-04-544  
Ein cyf/Our ref CS/01418/15

William Powell AM  
Assembly Member for Mid & West Wales  
Chair - Petitions Committee  
Ty Hywel  
Cardiff Bay  
Cardiff  
CF99 1NA

[committeebusiness@Wales.gsi.gov.uk](mailto:committeebusiness@Wales.gsi.gov.uk)

18 September 2015

Dear William Powell AM,

Thank you for your letter dated 18 June regarding petition P-04-544; ban the shooting of Greenland White-fronted geese (GWfG).

In your letter you explain the Committee agreed to write to me to pass on the latest correspondence it has received, seek my general comments on that correspondence and to ask me to reconsider the Welsh Government's position on a legislative ban on shooting this species.

I have very recently undertaken a review of the Welsh Government's position on this issue. Following a meeting between my officials and Natural Resources Wales, I received in July of this year a comprehensive briefing by Natural Resources Wales together with advice from my officials. I considered this carefully.

In Wales and England it is illegal to shoot GWfG during the close season (1 February – 31 August in, or over, any area below high water mark) but not during other periods of the year. However, there has been a long-standing, 40 year + voluntary ban on hunting GWfG by local wildfowling clubs on the Dyfi estuary. It is acknowledged by all parties that this voluntary shooting ban has been instrumental in protecting the birds there.

I understand that, during 2014, the British Association of Shooting and Conservation (BASC) worked with all wildfowling clubs across Wales to bring in similar voluntary bans on shooting GWfG on land over which the wildfowling clubs have specific rights to shoot. This is particularly important in north Wales and Anglesey because the birds migrate over these areas to reach the Dyfi. I have been advised that all BASC affiliated wildfowling clubs in Wales have now agreed a club rule preventing the shooting of GWfG.

We have no records or evidence of GWfG being shot in Wales between 2008/09 to the present. I have received no new evidence that suggests that these birds are currently being shot in Wales. The available evidence therefore suggests that the voluntary ban on the shooting of GWfG in Wales is being adhered to.

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Cardiff • Cardiff  
CF99 1NA

Wedi'i argraffu ar bapur wedi'i ailgylchu (100%)

English Enquiry Line 0300 0603300  
Llinell Ymholiadau Cymraeg 0300 0604400  
Correspondence: [Carl.Sargeant@wales.gsi.gov.uk](mailto:Carl.Sargeant@wales.gsi.gov.uk)

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I have therefore concluded that it is appropriate to maintain the current Welsh Government position which was agreed, following consultation, in 2013.

However, I have agreed that my officials should continue discussions with Natural Resources Wales and other stakeholders to both strengthen our evidence base concerning the ecology of the GWfG in Wales, and to support land management measures which will promote GWfG conservation in the Dyfi Valley and elsewhere in Wales. My officials are meeting NRW in early October to take this forward.

I believe that this approach will have a greater impact on the conservation of the GWfG in Wales than a statutory ban on shooting.

I will however keep the Welsh Government position under review, and if new evidence comes to light concerning the shooting of GWfG in Wales, then the option of pursuing a statutory prohibition on shooting GWfG in Wales will be reconsidered.

Yours sincerely,

A handwritten signature in black ink, appearing to be 'CS' or similar initials, written in a cursive style.

**Carl Sargeant AC / AM**

Y Gweinidog Cyfoeth Naturiol  
Minister for Natural Resources

# Agenda Item 3.7

**P-04-632 Mynyddoedd Pawb**

## **Petition wording**

We call on the National Assembly for Wales to encourage the Welsh Government to persuade bodies and organisations to protect and respect our wealth of place names in order to:

1) stimulate respect and interest in the Welsh language and to secure and increase the use of it.

2) increase the sense of identity among local communities by sharing the wealth of our cultural heritage with others.

3) engage the interest and awareness of visitors of the richness of our local heritage and thereby bring educational and economic benefits to areas.

This could be achieved through:

- working with outdoor centres in order to raise their awareness of traditional indigenous place names, and in order to support them to use Welsh place names in their day to day work.

- highlight the richness of our place names in terms of our cultural heritage, and what they can communicate through the teaching of history, geography, mythology and historical land use in our country.

- persuade the Welsh Government to bring traditional and long standing place names under planning control.

(A written petition is running concurrently.)

## **Additional Information**

We are of the view that that awareness should be raised of the importance of protection of Welsh place names, and that institutions and voluntary associations at local, regional and national levels have a key role in this.

Also, schools should ensure that children and young people have the opportunity to appreciate the richness of Welsh place names as part of their national heritage.

We believe that place names and the heritage and history associated with them, should be an integral part of environmental studies courses in further and higher education and outdoor pursuits courses run by other bodies. Training organisations, centres and clubs involved in mountaineering and outdoor activities should be encouraged to use Welsh place names.

We ask the National Assembly to stress the importance of all this to the Welsh Government, so that they can persuade local authorities, Natural Resources Wales, the National Trust, the National Park Authorities and other bodies in the statutory, voluntary, public and private sectors to take appropriate steps to safeguard Welsh place names.

**Lead petitioner:** Mynyddoedd Pawb

**First considered by the Committee:**

**Number of signatures:** 1,026

Ken Skates AC / AM  
Y Dirprwy Weinidog Diwylliant, Chwaraeon a Thwristiaeth  
Deputy Minister for Culture, Sport and Tourism



Llywodraeth Cymru  
Welsh Government

Eich cyf/Your ref P-04-632  
Ein cyf/Our ref KS/00802/15

William Powell AM  
Assembly Member for Mid & West Wales  
Chair - petitions committee  
Ty Hywel  
Cardiff Bay  
Cardiff  
CF99 1NA

committeebusiness@Wales.gsi.gov.uk

Dear William,

6 July 2015

Thank you for your letter on 18 June regarding Petition P-04-632 Mynyddoedd Pawb. I am responding on behalf of the Welsh Government regarding the protection of Welsh-language place-names.

I read the petition with interest and have shared your documents with relevant officials.

Welsh place names are valuable sources of evidence for informing the identification and management of historic assets. The Welsh Government is committed to promoting the Welsh language and recognises that people feel strongly about place names. However, we do not have direct responsibility for place-names or for the names of geographical features in Wales. Various public bodies, including local authorities and national park authorities, have a role in determining the official form and spelling of place-names and the names of geographic features in both languages.

With Tourism, Cadw and Culture now in the same portfolio, there are great opportunities to forge stronger working links across these areas which together clearly have a significant influence and role to play in making Wales a place that people want to visit and return to.

I am very much aware that Wales's countryside, coastline, culture, heritage and history comprise a major asset and strength in attracting visitors to Wales. This is being promoted and marketed effectively across many elements of the 'Have You Packed for Wales?' tourism marketing campaign; with detailed information on how to visit and experience many of these unique Welsh assets on the Visit Wales website.

Visit Wales has produced guidance for the tourism industry aimed at tourist destinations when applying for brown and white signs from the Motorway and Trunk Road Network. This

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English Enquiry Line 0300 0603300  
Llinell Ymholiadau Cymraeg 0300 0604400  
Correspondence: Ken.Skates@wales.gsi.gov.uk

Wedi'i argraffu ar bapur wedi'i ailgylchu (100%)  
Pack Page 138

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new guidance for tourist traffic signs focuses on local needs and offers greater flexibility in dealing with tourist signing on the trunk road and motorway network in Wales.

Work is underway to further develop a pan-Wales heritage interpretation plan. There are opportunities to link smaller and unlisted sites with Cadw sites to help join up and complete historic stories for example. Opportunities like this, along with accompanying cross-promotional work will be taken forward working with Cadw, site owners/mangers and stakeholders.

Cultural distinctiveness is important for tourism in Wales. Many tourists undertake cultural and heritage visits as part of their overall holiday experience. In supporting tourism businesses to develop we encourage businesses to provide a 'Sense of Place' that positively provides a Welsh experience for visitors. Experiencing a different culture and heritage often forms a lasting memory for visitors and helps to raise the awareness of Wales as a unique and diverse country. Our tourism marketing campaigns strongly feature and promote our heritage offer.

The Royal Commission on the Ancient and Historical Monuments of Wales is jointly running Cymru1900Wales.org which asks for volunteers to record all the place names of Wales as they appeared on Ordnance Survey maps at the end of the Victorian period. This is a ground-breaking, crowd-sourcing project which has been developed jointly by the Royal Commission, The National Library of Wales, University of Wales and the People's Collection Wales.

I am sure it will prove to be successful, and will pave the way for further collaborative research and online volunteering projects in the future which will all help with the aspirations behind this petition.

Through Curriculum Cymreig, it is a requirement across the curriculum that learners should be given opportunities to develop and apply knowledge and understanding of the cultural, economic, environmental, historical and linguistic characteristics of Wales. As an example, the History Curriculum contributes to this requirement by making local and Welsh history a focus of the study and helping learners to understand the factors that have shaped Wales and other countries today. Geography contributes to Curriculum Cymreig by offering opportunities for learners to explore by investigation and fieldwork the diversity of the natural and human landscapes in Wales.

*Yours ever,  
Ken*

**Ken Skates AC / AM**

Y Dirprwy Weinidog Diwylliant, Chwaraeon a Thwristiaeth  
Deputy Minister for Culture, Sport and Tourism



**Comisiwn Brenhinol Henebion Cymru**

**Royal Commission on the Ancient and Historical Monuments of Wales**

*Cofnod Henebion Cenedlaethol Cymru - National Monuments Record of Wales*

PLAS CRUG, ABERYSTWYTH, CEREDIGION, SY23 1NJ.

Ffôn / Telephone: +44 (0)1970 621200

Ffacs/Fax+44(0)1970 621246

[www.rcahmmw.gov.uk](http://www.rcahmmw.gov.uk)

National Assembly for Wales  
Petitions Committee  
Cardiff Bay  
Cardiff, CF99 1NA

Eich Cyfeirnod / Your Reference:

Ein Cyfeirnod / Our Reference: RCCG1-5-3

Dyddiad / Date: 30 June 2014

Dear Chairman,

**RE: Petition P-04-632 Mynyddoedd Pawb**

I am very grateful for the opportunity to comment on this petition and I congratulate Mynyddoedd Pawb for having brought to public attention a matter of great importance. I believe that this is a matter of fundamental historical principle which is relevant to the whole of the United Kingdom, but of course it applies directly when there is a danger of a 'new' name being created by incomers or visitors from outside a local culture in ignorance or in defiance of an existing name in the historical language, as is now happening in Wales. There are very few parts of the Welsh landscape that do not have a Welsh name, known to local people and used over many centuries, even if these names have not been recorded officially, and those names are either geographic indicators or have historical significance. I have in mind an example that I pass every time I travel from Cardiff to Aberystwyth, where there is a farm which has been known for centuries by the geographically-descriptive name 'Gwarallt', meaning 'brow of the hill'. I have observed a riding business set up and putting its 'trade name', 'The Bitless Bridle Riding Centre' next to the farm name. Over the years the farm nameplate has slipped until it has now been taken away – and a traditional and meaningful name has disappeared from sight. We now know that there is a real danger that newly created names, particularly for geographic features in the most attractive parts of the countryside, are being accepted by the Ordnance Survey and therefore are supplanting the traditional names with official support.

The Royal Commission would support all the measures that are mapped out in the petition, and in particular the simple and no-cost solution of bringing traditional and long-standing place names under planning control; that is to say, that all planning applications should use the traditional names and permission should not be given to a change of name in which a new coinage replaces an existing name.

This is consistent with the position that the Royal Commission adopts in all its record keeping; more than that, we are partners in a very successful and well-supported project called Cynefin: Mapping Wales' Sense of Place in which volunteers are helping us to add traditional names to a series of modern and historic maps. It would be a tragedy if the use of these names was limited to an archive – traditional Welsh names are usually descriptive of the topography, and as the petition makes clear, are often the catalyst by which non-Welsh speakers begin to acquire a knowledge of the language, through their growing familiarity with the place-name elements they encounter on road signs and maps.

I think that the requests that are being made by this petition are important and reasonable and do not depend upon large sums of new money being made available. They are also entirely consistent with the Welsh Government's National Action Plan for a Bilingual Wales.

Yours sincerely,



Dr Eurwyn Wiliam MA., PhD., FSA  
Chairman, Royal Commission on the Ancient and Historical Monuments of Wales



William Powell AM  
Chair  
The Petitions Committee  
National Assembly for Wales  
Cardiff Bay  
Cardiff CF99 1NA

15/09/2015

Dear Mr Powell,

**P-04-632 Mynyddoedd Pawb**

Thank you for your letter asking for my opinion on the petition submitted by Mynyddoedd Pawb. Before responding, I'd like to outline my office's activity in relation to place names.

1. The Commissioner's main goal is to promote and facilitate the use of Welsh. This is done by highlighting the fact that the Welsh language has official status in Wales and by setting standards for organisations. This in turn will lead to establishing rights for Welsh speakers.

Two principles underpin the Commissioner's work:

- Welsh should be treated no less favourably than English in Wales;
- People in Wales should be able to live their lives through the medium of Welsh if they wish to do so.

Over time, new powers to set and enforce standards for organisations will come into force through subordinate legislation. Until that happens, the Commissioner will continue to inspect statutory language schemes through the powers she inherited from the 1993 Welsh Language Act.

The Commissioner's role was created by the Welsh Language (Wales) Measure 2011. The Commissioner may investigate failure to implement a language scheme; interference with the freedom to use Welsh in Wales and, in future, complaints about the failure of organisations to comply with standards.

Comisiynydd y Gymraeg  
Siambrau'r Farchnad  
5-7 Heol Eglwys Fair  
Caerdydd CF10 1AT

0845 6033 221

post@comisiynyddygyymraeg.org

Croesewir gohebiaeth yn y Gymraeg a'r Saesneg

comisiynyddygyymraeg.org

Welsh Language Commissioner  
Market Chambers  
5-7 St Mary Street  
Cardiff CF10 1AT

0845 6033 221

post@welshlanguagecommissioner.org

Correspondence welcomed in Welsh and English

welshlanguagecommissioner.org

One of the Commissioner's strategic objectives is to influence the consideration given to the Welsh language in the development of policy and legislation. So, one of the Commissioner's main functions is to provide comments in line with these terms of reference, acting as an independent advocate for Welsh speakers in Wales who may be affected by the proposed changes. This approach is taken in order to avoid any potential compromise of the Commissioner's regulatory functions, and if the Commissioner were to formally review the performance of individual organisations or the Welsh Government in accordance with the provisions of the Measure.

## **2. The Commissioner's activity in relation to place names**

*A living language: a language for living*, the Welsh Government's Welsh Language Strategy 2012-17, states that the Welsh Language Commissioner has responsibility for coordinating developments in relation to Welsh place names. The Welsh Language Commissioner is also responsible for providing advice on the standard forms of place names in Wales. This responsibility was inherited when the Welsh Language Board was disbanded in 2012. The Commissioner has no statutory powers in this area and her recommendations and advice have no legal force, but recommendations on the standard forms of place names are provided for all kinds of agencies, including the Welsh Government and local authorities. The Commissioner has a panel of experts, namely the Place Names Standardisation Panel, which supports the work of the Commissioner and advises on the standard forms of place names. The Commissioner's work in this area focuses on the names of settlements (towns, villages, etc.) rather than features of the landscape (mountains, rivers, etc.) or physical features of human activity, such as buildings etc.

3. I have no specific responsibility in relation to the protection or promotion of Welsh place names. However, I am aware of the concerns expressed in the petition and I would be supportive of the principles underlying the need to protect and respect our wealth of place names in order to:

1. *Stimulate interest in and respect for the Welsh language, and to ensure and increase its use*
2. *Increase the sense of identity among local communities by sharing our wealth of cultural heritage with others*
3. *Engage visitors' interest and awareness of our wealth of local heritage and thus bring educational and economic benefits to areas.*

One could argue that there is at least a moral responsibility on organisations to protect and respect Welsh place names because they are national institutions that have a duty to reflect the history and culture of the country. In principle, therefore, I wouldn't oppose any reasonable steps that could be taken by the organisations named in the petition to protect Welsh place names. As a minimum, the Welsh Government could provide specific guidance to the organisations that it funds directing them to use names in their correct form and to consult with a suitable organisation in determining those names. In a similar vein, I would support action to raise awareness of place names and local heritage in outdoor education and training courses at all levels.

4. I note that the petition specifically asks the Welsh Government to bring long-standing and traditional place names under planning control. In order to make that possible, there would need to be a method of deciding which names should come under planning control. For that to happen and in order to provide specific guidance to the agencies referred to in the petition, I assume a body would need to be established that would be responsible for deciding those names. That body would need to set very stringent criteria as to how it would determine these forms, and the official forms should be published in a public register. It could also determine the official names of other locations in Wales which could be of wider benefit in terms of mapping, transport, planning, addresses, emergency services, communication etc. This body could encourage the use of names by public bodies as well as individuals and organisations from the third sector and the private sector.
  
5. Since it is a matter of concern to so many, I think we need more research into possible methods of protecting Welsh place names and that can be done by taking account of similar activities in other countries. If, for example, you intend to consider establishing a body to facilitate bringing these names under planning control, I suggest that you look at what has happened as regards determining place names in other countries including Canada and Australia (including the states of New South Wales and Victoria). These countries have introduced legislation to establish specific boards that are responsible for setting standard name forms for the benefit of mapping activities, planning and infrastructure. These boards publish the name forms on a public database. In New South Wales, for example, it is an offense to use any names for particular locations in any kind of publication if they have not been published on the public database<sup>1</sup>.
  
6. Recently in my response to the Communities, Equality and Local Government Committee consultation on the Historic Environment (Wales) Bill, I proposed an amendment to the Bill requiring that historic environment records, which local authorities will have a duty to publish, should contain the details of each area, site or other location in the authority area which has a name of historical and cultural interest. I have noted that the *name* of a physical feature of human activity should be a reason to protect the feature in the historic environment, thereby protecting the name of the feature. I have also noted that the Advisory Panel for the Welsh Historic Environment established by the Bill should include an expert on place names. I enclose a copy of my response to that consultation. At the Communities, Equality and Local Government Committee meeting on 8 July 2015, the Deputy Minister for Culture, Sport and Tourism, Kenneth Skates AM, said he would be willing to "take any suggestions and any recommendations and consider them with regard to the historic environment records"<sup>2</sup>.

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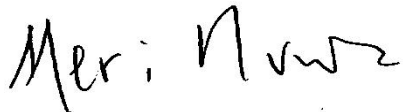
<sup>1</sup> [http://www.austlii.edu.au/au/legis/nsw/consol\\_act/gna1966158/s15.html](http://www.austlii.edu.au/au/legis/nsw/consol_act/gna1966158/s15.html) [accessed 31/07/2015]

<sup>2</sup> <http://abms/documents/s42561/8%20July%202015.pdf>

7. It should also be noted that during the Communities, Equality and Local Government Committee's deliberations on the above Bill on 2 July 2015, Rhodri Glyn Thomas AM asked whether it would be possible to consider "a consent regime for name changes" and asked for a legal note on the matter. The committee Chair, Christine Chapman AM, said that the Committee would look into the matter. I imagine that the results of that research could be useful to you in your consideration of this petition.

I thank you for this opportunity to comment on the above petition submitted by Mynyddoedd Pawb. I know it is a concern in communities across Wales that all kinds of place names are being changed, thereby losing an important link to the history and heritage of those areas. Usually, but not always, those names are ones that were originally Welsh. In line with the Welsh Language (Wales) Measure 2011, Welsh is now an official language in Wales. It is a matter of genuine concern that Welsh place names are being undermined and that Welsh is being treated less favourably on the ground at the exact same time as it becomes an official language in the eyes of the law. Positive action to prevent this from happening and protect place names would be an important step forward.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Meri Huws'. The signature is written in a cursive, slightly slanted style.

**Meri Huws**  
Welsh Language Commissioner

Enc.



Clerk to the Committee  
Communities, Equality and Local Government Committee  
National Assembly for Wales  
Cardiff Bay  
CF99 1NA

SeneddCCLLL@Cynulliad.cymru

19/6/2015

Dear Clerk,

### **Consultation on the Historic Environment (Wales) Bill**

1. The Welsh Language Commissioner welcomes the opportunity to comment on the Historic Environment (Wales) Bill. The following comments relate specifically to the principles of the Bill in relation to the physical traces of past human activity in the historic environment in Wales. Specifically it is asked that:
  - o The names of the physical traces of human activity should be a reason to protect such features in the historic environment, and in doing so protect the names of the feature. In that respect the historic environment records should include the details of each area or site or other location in the authority with a name which is of historical and cultural interest.
  - o The guidance issued by the Welsh Government on the discharge of the duty to create a historic environment record should include specific guidance regarding the names of the features included in the records and the language of the records.
  - o Welsh Ministers should consult experts on orthography and place names before issuing the guidance.
  - o The Advisory Panel for the Welsh Historic Environment should include place-names expertise.
  - o The Committee should consider whether there is a means of protecting place-names either by amending the scope of the Bill or introducing other methods or further legislation.
2. The principal aim of the Commissioner is to promote and facilitate the use of the Welsh language. This entails raising awareness of the official status of the Welsh language in Wales and imposing standards on organizations. This, in turn, will lead to the establishment of rights for Welsh speakers.

Comisiynydd y Gymraeg  
Siambrau'r Farchnad  
5-7 Heol Eglwys Fair  
Caerdydd CF10 1AT

Welsh Language Commissioner  
Market Chambers  
5-7 St Mary Street  
Cardiff CF10 1AT

0845 6033 221  
post@comisiynyddygybraeg.org  
Croesewir gohebiaeth yn y Gymraeg a'r Saesneg

0845 6033 221  
post@welshlanguagecommissioner.org  
Correspondence welcomed in Welsh and English



Two principles underpin the work of the Commissioner:

- In Wales, the Welsh language should be treated no less favourably than the English language;
- Persons in Wales should be able to live their lives through the medium of the Welsh language if they choose to do so.

In due course, secondary legislation will introduce new powers allowing the setting and imposing of standards on organizations. Until then, the Commissioner will continue to inspect statutory language schemes through the powers inherited under the Welsh Language Act 1993.

The post of Commissioner was created by the Welsh Language (Wales) Measure 2011. The Commissioner may investigate failure to implement a language scheme; interference with the freedom to use Welsh in Wales and, in future, complaints regarding the failure of organizations to comply with standards.

One of the Commissioner's strategic objectives is to influence the consideration given to the Welsh language in policy and legislative developments. Thus, one of the Commissioner's principal roles is to provide comments in accordance with this remit, acting as an independent advocate on behalf of Welsh speakers in Wales who might be affected by these proposed changes. Such an approach is advocated to avoid any potential compromise of the Commissioner's regulatory functions and should the Commissioner wish to conduct a formal review of individual bodies' performance or the Welsh Government's performance in accordance with the provisions made in the Measure.

### 3. The Commissioner's activities in the field of place-names

*A living language: a language for living, the Welsh Government's Language Strategy 2012-17* states that the Welsh Language Commissioner will 'coordinate the standardisation of Welsh place-names'. The Welsh Language Commissioner also has a responsibility to provide advice on the standard forms of Welsh place-names. This responsibility was transferred to the Commissioner when the Welsh Language Board came to an end in 2012. The Commissioner has no statutory powers in the field and its recommendations and advice have no legal force, but recommendations on the standard forms of place-names are provided to organizations of all kinds, including the Welsh Government and local authorities. The Commissioner has a panel of experts, the Place-names Standardization Panel that supports the work of the Commissioner in recommending the standard forms of place-names. The Commissioner's work in this area focuses on the names of settlements (towns, villages etc.) rather than on names in the landscape or the names of physical traces of human activity such as buildings etc.

### 4. Historic Environment (Wales) Bill – definition of monuments (section 22)

Section 528 of the explanatory memorandum for the Historic Environment Bill (Wales) sets out that 'the focus of the Historic Environment (Wales) Bill is on the protection and sustainable management of the physical remains of the first human activity in the historic



environment — including archaeological sites, monuments and historic buildings'. It also states that the 'protection of place names falls outside the scope of the Bill'. While the focus of the Commissioner's work is on the names of settlements as explained above, the following comments deal with the relationship between names and the physical traces of past human activity on historical sites.

There is considerable concern in many communities in Wales that the names of historical houses and buildings, which are names that are as old as the buildings themselves, are being changed. The meaning and origin of the name of a feature in the historic environment can reveal much about it, including its origin and provenance; the historical use made of it; who lived or used it; how and with what it was constructed etc. This has implications for the historic environment because the names of the physical features of human activity are, as much as the features themselves, 'a precious and irreplaceable legacy for the nation [...] have left an imprint on our national culture and identity by [...] generating a sense of place and belonging' as set out in section 6 of the explanatory memorandum to the Bill. Indeed it could be argued that the danger and risk to the survival of some of these names is equal in some cases to the risk to the survival of the historic environment itself.

With this in mind, Section 22 of the Bill extends the definition of a scheduled monument in the Ancient Monuments and Archaeological Areas Act 1979 to include 'any site in Wales comprising any thing, or group of things, that evidences previous human activity.' The name of a feature in terms of its meaning and provenance is evidence of previous human activity. Although the Explanatory Memorandum sets out that the protection of place-names falls outside the scope of this Bill, it is a pity therefore that there is no intention of doing so in the Bill. This could be done, for example by defining monuments because of the value of their names as evidence of past human activity, or by maintaining a register of names which are of historic importance, in the same way that there is an intention to maintain a register of historic parks and gardens (Section 18). I ask the Committee to consider ways of protecting place-names, either by extending the scope of this Bill or by introducing other methods or further legislation.

#### **5. Historic Environment Records (Section 44, 33 of the Bill)**

Section 44 of the Bill states that 'each local planning authority in Wales must create and keep up to date a historic environment record'. Section 33(h) of the Bill states that the historic environment record must include 'details of every other area or site or other place in the authority's area which the authority considers to be of historic, archaeological or architectural interest'. A draft version of the guidelines for the creation of historic environmental records has been made available alongside this Bill. I note that the guidelines explain that an association with a place-name could mean that a feature is included in the historic environment record. I ask that you therefore consider including a specific definition in the Bill that states that the historic environment record should include the details of every other area or site in the authority's area which is of 'toponymical interest', or that its name is of 'historical and cultural importance'.



## 6. Guidance (Section 4, 36 of the Bill)

Section 36 of the Bill gives details of the guidance given by the Welsh Government on the discharge of the duty to create a historic environment record. The guidance should state specifically that the records should be bilingual and of the same standard in Welsh and English in accordance with the requirements that will be made of local authorities under the Welsh Language (Wales) Measure 2011.

I ask that the guidance also specifies the need to give due attention to the orthographic accuracy and source of the names of the features included in these records and that the Welsh or English names, or the names in both languages if they exist<sup>1</sup> are published. They are public records and should therefore be correct, not only from a historical point of view, but also from a linguistic point of view in order to avoid any ambiguity. I recommend that the guidance includes the need to consult with experts on language and place-names when creating the historic environment records.

The draft guidance published also deals with information technology in terms of public access and compliance with data standards. The guidance should refer specifically to the need to maintain and share bilingual data and provide bilingual on-line services in accordance with the Welsh Language (Wales) Measure 2011. A non statutory guidance on considering the Welsh language and bilingualism in technology, website and software is available on the Commissioner's website<sup>2</sup>.

I also ask that the guidance states that the owners of the physical features that are recorded should not change their names because their names and their provenance are integral parts of the features themselves.

36 (3) (b) sets out that Welsh Ministers must consult with 'such other persons as the Welsh Ministers consider appropriate' before issuing guidance. I recommend that these persons should include experts on place-names and Welsh orthography.

## 7. Advisory Panel on the Welsh Historic Environment (Section 4, 37)

The Bill requires that Welsh Ministers establish an Advisory Panel on the Welsh Historic Environment with the purpose of providing Welsh Ministers with 'advice on matters relating to the formulation, development and implementation of policy and strategy in relation to the historic environment in Wales'. As noted above, the names of physical features give cultural and historical value to the features themselves and the origin and orthography of these names are key issues when formulating, developing or implementing policy and strategy for the historic environment. Therefore, the Panel should give due regard to the need to protect the names of the historic environment. To enable this, the Panel should consult with specialists in the field of place-names when compiling its work programme and should ideally include at least one member with expertise in this field.

<sup>1</sup> The names of physical traces of human activity will either be in Welsh only (the majority), in English only or in some rare cases bilingual. They do not need to be bilingual if they are only in one language.

<sup>2</sup> *Technoleg, Gwefannau a Meddalwedd: Ystyried y Gymraeg*, <http://www.comisiynyddygymraeg.org/English/Publications%20a%20Technoleg%20a%20Gwefannau%20a%20Meddalwedd%20-%20Technology%20a%20Websites%20and%20Software.pdf> (accessed 17 June 2015)



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Welsh Language  
Commissioner

8. I understand that this Bill does not intend to protect place-names, topographical names or the names of physical traces of past human activity in Wales. However, I believe that it is necessary to protect these names as far as possible because of their cultural and historical significance, as well as their importance to communities. I believe that the amendments recommended above acknowledge the historical importance of the names of physical traces of past human activity and recognize that the names in themselves should be reason enough to protect features, thus protecting their names. If the Committee is not of the opinion that these recommendations should be accepted, I would ask it to consider whether it believes that Welsh place-names need to be protected and how it would propose to do so.

Thank you for the opportunity to submit written evidence to you regarding the Historic Environment (Wales) Bill.

Yours sincerely,

**Meri Huws**  
Welsh Language Commissioner

## Further consideration of the Mynyddoedd Pawb Petition (P-04-632)

6 October 2015

### Comments from *Mynyddoedd Pawb* following the latest correspondence to the Petitions Committee

#### Royal Commission on the Ancient and Historical Monuments of Wales

We are pleased with the support of the RCAHMW and its recognition that: "Traditional Welsh names .... are often the catalyst by which non-Welsh speakers begin to acquire a knowledge of the language, through their growing familiarity with the place name elements they encounter...".

#### Deputy Minister for Culture, Sport and Tourism

We are pleased that the Deputy Minister accepts that Welsh place names are important resources in terms of identifying and managing our historical assets and that they add to the cultural distinctiveness of Wales.

#### Welsh Language Commissioner

We agree with the recommendations of the Welsh Language Commissioner that:

- A board or body should be established to deal with issues relating to names, and to set criteria for planning purposes
- The traditional names of landscape features and buildings of all kinds, as well as listed buildings, should be safeguarded.

We believe that such a board or body should be responsible for:

1. Proposing standard forms, and by means of a local consultation process, recognising forms in local dialect when appropriate.
2. Recording place names and ensuring that they are consistent in official documents and maps. There should be close co-operation with the OS to ensure the accuracy and appropriateness of names.
3. Implementing a consultation procedure with regard to changing names, working on a catchment area level, i.e. the planning authorities across Wales. One example is that of an immigrant who wanted to remove a Welsh name, and when he was asked why, his answer was: "I could not care two hoots about your Welsh name", and he changed the name to 'Two Hoots' (this name change is recorded in the evidence of *Cymdeithas Enwau Lleoedd Cymru (The Welsh Place Name Society)* to the Communities, Equality and

Local Government Committee meeting on 2 September). We believe that, in order to protect our heritage from such disrespect, name changes should be allowed only by agreement of the local community and the local planning authority.

### **Responses not received**

We are disappointed that no response has yet been received from the *Welsh Tourist Board (Visit Wales)* and the *Wales Tourism Alliance*. We kindly ask you to contact them again.

We ask once again for consideration to be given to the objectives of the petition by the **Minister for Culture, Sport and Tourism**, the **Education Minister** and the **Minister for Natural Resources and Planning**, and the **First Minister of Wales**, who is responsible for the **Welsh language**. In order to meet the objectives contained in our petition, co-operation between all the above departments is essential.

We also ask you to contact *Cadw*, the organisation which is responsible for protecting, through legislation, over 30,000 listed buildings and over 500 special architectural conservation areas throughout Wales. They do commendable work to protect the architectural integrity of these sites, but we are greatly concerned that they are not equally keen to protect the names of such sites. Names are just labels in Cadw publications, with no recognition of the cultural importance of the names.

Is the name not an integral part of the character of what is protected, enabling it to be placed in its appropriate historical and cultural context? Traditional names of buildings and all types of landscape features should be protected. This already takes place in other European countries out of respect for native culture and to preserve the character of the sites that visitors yearn to see.

### **Our petition aims:**

**To stimulate interest in the Welsh language and a respect for it, and to safeguard and increase the use of the language.**

Explaining the meanings of place names to non-Welsh speaking immigrants to an area could be a first step to welcoming them and introducing them to

the wealth of our heritage. For example, sessions to welcome people, and to enable them to socialise in the village of Nebo, in the Nantlle Valley, have been hosted by Mr O P Huws. Learning the meaning of the names of their own houses and the houses of neighbours, and who used to live in the houses, have proved very popular over the years. As a result, many of the newcomers have joined Welsh language classes and have integrated fully into **the** local community.

We need to celebrate the richness of our place names by ensuring that our cultural heritage is alive for everyone. Through **the latest technology**, which is developing daily, we can also present the wealth of our culture and language through the names of our landscapes. This could be just as attractive to Welsh speakers, Welsh learners and those who are interested in the language.

Discussions and joint working are currently taking place between *History Points*, the *Wales Coastal Path*, the *Place Name Society*, *Cymdeithas Edward Llwyd* and *Menter Iaith Conwy* (the Conwy Language Initiative).

As well as organised trips, the correct pronunciation of names in our landscapes could be provided to interested parties. There is also an opportunity here to go a step further, and to introduce **contemporary Welsh culture** to a wide audience. We suggest working with popular Welsh learning initiatives such as *Say Something in Welsh*.

**2. To increase the sense of identity among local communities by sharing the wealth of our cultural heritage with others.** Voluntary and public sector statutory bodies need to protect cultural heritage and show pride in our invisible as well as our visible heritage, which would provide an interesting variety to local people and visitors in terms of their perspective on the environment.

**3. Stimulate an interest and an awareness of the richness of our local heritage among visitors, thereby bringing educational and economic benefits to the local area.**

Welsh place names are amongst the most visible elements that tourists in Wales

appreciate, and that emphasise the distinctiveness of Wales. Some specific place names themselves attract tourists, e.g. Llanfairpwllgwyngyll ... .. and Beddgelert, while others can add greatly to cultural experience.

For example, very successful residential courses have been organised for several years at *Plas Tan y Bwlch*, Maentwrog on *The Mabinogion* tales. These courses are held in Welsh and in English. They focus on the 4th Tale: The Legend of Math Fab Mathonwy (story of Llew Llaw Gyffes, Blodeuwedd etc). An essential part of the course is to visit 15 sites in the Nantlle Valley and Ffestiniog area named in the legend. Similarly, field trips have also been organised as part of courses at Nant Gwrtheyrn the *Language Centre*.

**Education** in schools should ensure that children and young people have the opportunity to appreciate the wealth of our Welsh place names as part of their heritage, by **teaching** history, geography, mythology and historical land use in Wales.

Place names are an extremely useful means of giving added value to people and children's experience of history and the environment, in the countryside and in towns, through outdoor activities and field studies. The descriptive elements in names of landscapes and habitats enrich the appreciation of geographical and ecological features on field work exercises for schools.

Place names serve as a means to present the wealth of our heritage through their connections in history and legend, e.g. names of mountains, streams, lakes underpin many of our tales and legends.

(Further evidence available from Education Officers at *Glanllyn*, the Urdd youth organisation Camp, and *Snowdonia National Park Centre*, Plas Tan y Bwlch, Maentwrog, Gwynedd, *Menter Iaith Conwy*, the *Antur Stiniog* initiative and also *Blaenau Ffestiniog Youth Club*).

Place names are instrumental in knowing the landscape, and enhancing the enjoyment of walking and socialising outdoors, with obvious benefits to people's health and well-being (Further evidence is available from *Cymdeithas Edward Llwyd* (naturalists' society) and *Clwb Mynydda Cymru* (*Wales Mountaineering Club*))

Place names along with the heritage and history associated with them, should be an integral part of environmental study courses in **further and higher education**, and outdoor activities courses such as mountain leadership courses that are run by other organisations. Similarly, we should

work with outdoor activity centres in order to raise awareness of the richness of traditional indigenous place names, and to support their use of Welsh place names in their day-to-day activities.

We call upon the National Assembly for Wales to urge the Welsh Government: to promote and regulate the use of Welsh names on maps, signage and websites, to influence public bodies to use the indigenous name on each occasion, to encourage leisure and outdoor recreation organisations (which are often financed from public funds) to use the indigenous names and to include cultural heritage as part of their package to the visitor.

With the tremendous growth in the number of Welsh speakers who earn a living in the outdoor and environmental tourism sector over the last decade (**Evidence available from *Menter Iaith Conwy***) we are more aware than ever of the importance of protecting and promoting the indigenous place names in order to withstand the increasing threat from climbers, kayakers, surfers, mountain bikers etc. who invent English names for climbs, ponds and trails and disregard original Welsh names. This in turn weakens the cultural distinctiveness of our country.

We would like to note that the National Heritage Lottery Fund in Wales and Cornwall acknowledges that place names are a full element to be considered in the financing of their heritage portfolio. We hope that the Welsh Government will follow suit.

We ask the National Assembly for Wales to stress the importance of all of this to appropriate Ministers in the Welsh Government, providing guidance, so that they can persuade Local Authorities, Natural Resources Wales and National Park Authorities, together with other organisations in the statutory, public, voluntary and private sector, to take these appropriate and far-reaching steps to protect and celebrate this national heritage by means of the Welsh names of our landscape.

We look forward to positive discussions.

Appendix:

Response of the Snowdonia National Park to *Wales Tourism Alliance* comments following an interview on Radio Wales on 12/05/15

## **SNOWDONIA NATIONAL PARK AUTHORITY**

Press Release

Wednesday, 13th May 2015

### **Snowdonia National Park Authority: Object to the comments of the Welsh Tourist Alliance.**

**At a meeting at Plas Tan y Bwlch, Maentwrog today (Wednesday, 13th May, 2015), Members of the SNPA resolved to declare that the Authority strongly disagrees with the comments of the Chair of the Wales Tourism Alliance regarding the use of the Welsh language in welcoming visitors to Wales.**

On behalf of the Authority, its Language Champion, Councillor Elwyn Edwards said:

"As an Authority, we support the campaign of Mynyddoedd Pawb and we call on the Welsh Government to ensure that Welsh names are protected and promoted.

Welsh names are part of our cultural heritage – they reflect aspects of our history, our landscape, our biodiversity, our language and our way of life. These qualities are

the things that make us special, distinctive and attractive to visitors. It is therefore interesting to note the Welsh Government's announcement yesterday that 2014 was a record year for Wales in terms of tourism, as the number of British visitors to Wales reached 10 million.

There were no complaints from any of these visitors that the Welsh language was 'in the way' or a barrier of any kind.

As an Authority, our job is to protect our heritage and Welsh place names are a core element of our local heritage. If we lose our names, we will lose our history and our heritage.

In the past, the WTA has recognised the importance of the National Parks' statutory purpose in protecting and enhancing the beauty, wildlife and cultural heritage of their areas. Therefore, we are disappointed to hear the destructive comments of the Chairman of the Alliance, which contradict this."  
End

#### Note to Editors

1. "Mynyddoedd Pawb" want the Welsh Government to protect and respect the wealth of place names in order to:
  - Stimulate interest in the Welsh language and a respect for it, and to safeguard and increase the use of the language.
  - Increase the sense of identity among local communities by sharing the wealth of our cultural heritage with others.
  - Stimulate an interest and an awareness of the richness of our local heritage among visitors, thereby bringing educational and economic benefits to the local area.
2. For further information, or to arrange an interview, please contact Llinos Angharad, Media and Events Officer, Snowdonia National Park Authority on 01766 772237 or 07766 255509.

# Agenda Item 5

By virtue of paragraph(s) ix of Standing Order 17.42

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