

A consultation on the provision of specialist residential chronic pain services in Scotland

September 2013

Ministerial Foreword



It is now five years since the Scottish Government recognised chronic pain as a condition in its own right. For those with chronic pain, either as an individual, as a family member or carer, we know that the condition has a profound effect on their day to day quality of life.

I am pleased that we've made progress in our Scottish chronic pain services, but I'm quite clear there is more to do. We have developed a Scottish Service Model for Chronic Pain, which sets out the sort of service we want people to have. The model intends to address many of the concerns highlighted in the 2007 report ["Getting to GRIPS with chronic pain in Scotland"](#). Whilst we know there is some improvement in service provision we also know variation persists, something I want to see improved. To help with this, funding for all NHS Boards to establish service improvement groups has now been approved by Scottish Government. These groups are led by healthcare staff and managers and importantly include patients who want to see improvements in their local services. We have asked that patients are involved in these groups, so that services can take account of and include their views.

But, there's more that the Scottish Government can do and one area where I have made a clear commitment to do this is to ensure Scotland has its first specialist residential chronic pain service.

Currently, people who need this, and we recognise some can't even make the journey so they could benefit, go to the Royal National Hospital for Rheumatic Diseases in Bath, where they get specialist treatment and residential accommodation over a 2 – 4 week period.

As I pledged at the Parliamentary debate on Chronic Pain Services on 29 May this year, the Scottish Government intend to address this by ensuring we have this type of service available in Scotland. I am very heartened that this was backed unanimously by the Parliament.

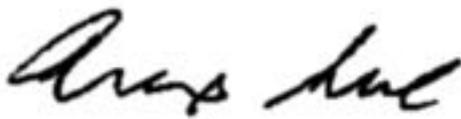
In the debate Mr Matheson, Minister for Public Health, and I highlighted there are a number of ways the service could be delivered. Various options are set out for you to consider in this consultation paper. To help inform a decision on the most

appropriate one I am seeking a wide range of views from patients, their families, carers, clinicians and other stakeholders. None of the options presented are mutually exclusive and whichever one or combination is selected we will ensure that the service is accessible throughout Scotland, including for those living in remote and rural areas, as well as large towns.

Some of you will know that we launched the consultation in July, however we recognised from early feedback that the consultation document was not as clear as we would like. As I place such importance on having this service in Scotland I asked that the document and respondent form be redrafted to take account of the helpful feedback we received.

It is unfortunate that this will mean the timescales for a decision will be delayed but I really do want people with an interest to respond. We will also be arranging some events in different parts of the country to ensure we try and reach as many people as possible.

I therefore look forward to hearing your views on the options in this paper, or indeed, if there are others that you think should be considered we are keen to hear about these as well.

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

Alex Neil MSP
Cabinet Secretary for Health and Wellbeing

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CHAPTER 1: Introduction and background

Introduction

This consultation focusses on those patients who may benefit from treatment provided by creating a specialist residential service in Scotland. This type of service is designed to improve quality of life, enable patients to better manage their chronic pain and reduce their disability.

We know that around 800,000 people in Scotland live with chronic pain to varying degrees. It is defined as pain that has lasted for over 12 weeks and continues beyond the time in which healing /recovery would normally take place. It can have a considerable impact on individuals and family members and can result in significant impairment, disability and sometimes depression. It is also a major clinical challenge for NHSScotland.

The quality of life, mood, ability to sleep, general wellbeing and mobility of people who experience chronic pain can be greatly improved by appropriate treatment. In some cases, this can be achieved through a specialist residential service.

Why does Scotland need a specialist residential service(s)?

In a debate in the Scottish Parliament a clear commitment was given by Mr Alex Neil, Cabinet Secretary for Health and Wellbeing, to provide the first specialist residential service in Scotland. He also stated that a public consultation would take place on how this could be provided so that a wide range of views could be established.

The service will fill a gap in current service provision in Scotland and will stop patients, who are clinically assessed as likely to benefit, from having to travel long distances outside Scotland, first for assessment and then for treatment.

Currently Scottish patients who require this intensive service are referred to the Bath Centre for Pain Services in Somerset. However, there are patients in Scotland suitable for this level of treatment who are unable to access or benefit from it. This is for a number of reasons, for example:

- inability to withstand travelling long distances to Bath or elsewhere in the UK, first for a 2-3 day assessment and then returning for 2-4 weeks of treatment;
- being away from family or carers for 2-4 weeks of intensive treatment;
- having few, if any, visitors as most of these will be in Scotland;
- for some, paying for travel costs upfront can be an additional barrier (although repaid to those on certain benefits or low income, upfront costs prevent some patients from accepting).

As such, these combined factors mean there is likely to be an unmet need for a specialist residential service. It is therefore anticipated that a Scottish service is likely to grow in the future.

What does a specialist residential service do?

The service is intended to increase an individual's self-confidence and their ability to self-manage and cope with their pain. Through understanding and coping better this makes day to day living easier and often reduces disability. This level of service is set out within the Scottish Service Model for Chronic Pain (Annex B page 19).

Patients who are most likely to benefit will usually fall into the following groups:

- those with chronic complex pain and associated problems, such as depression.
- those patients with severe chronic pain in an area where geographical or other logistical factors make it practically impossible to attend a local service on a regular (usually weekly) basis.

While in many cases a total 'cure' is not likely the skills gained can greatly improve patient's general well-being, mood, mobility and sleep enabling them to have a better quality of life. The treatment is provided daily over a 2-4 week period, with nearby residential accommodation.

This type of service includes:

- one to one assessment by clinicians and other health care workers trained in chronic pain issues.
- guided one to one sessions which offer support and challenge at the same time as encouraging self-exploration of new activities or different ways of doing routine day to day things.
- assessment and management of medication to enable people to gain the greatest benefit from these.
- group sessions involving discussion and the sharing of experiences.
- programmes of exercise tailored to individual ability.

Such a service is not an alternative or a substitute for the provision of locally delivered chronic pain services, either in primary or secondary care.

What does a Scottish service need to include?

Following an assessment of the residential service in Bath it is anticipated that a Scottish service should include the following key components:

1. Staff trained and skilled in chronic pain who work as part of a specialist (multi-disciplinary) team. This would include medical specialists, clinical psychologists, specialist nurses, physiotherapists and occupational therapists. The actual number and mix of staff will be dependent on the service model adopted. The consultation response will help to inform this.
2. Fit for purpose accommodation – for both treatment and residential facilities.

Space will be needed so that individuals can take part in the treatment activity, whether working in groups or individually. This would require:

- Occupational therapy space, including kitchen/bathroom area(s).
- An accessible nearby physiotherapy gym.
- Rooms large enough to accommodate group activity work.
- Access to consultation rooms for one to one work.

In addition to the treatment space described residential accommodation would also need to be provided. Local accommodation would be offered to those who wish to stay. The treatment space and accommodation would need to comply with the Equalities Act (2010).

How will the new Scottish service be supported at a local level?

Regardless of the service model adopted, the new service will need to be supported by an improvement to local chronic pain services. All NHS Boards are already working towards improving care and access to their local services as set out in the Scottish Service Model for Chronic Pain. This includes provision of education and support for individual self-management, support from third sector organisations, access to pain services through primary care teams and referral to local specialist pain services in hospitals and other outpatient settings.

Care will need to be taken that the availability of the new service does not result in a lack of investment by NHS Boards to improve their local services.

What will happen until a Scottish service is in place?

From those who have participated we know that there is a high level of satisfaction with the service provided in Bath. This is also supported by evidence that positive outcomes are achieved. As such in the interim, up until a Scottish service is developed, patients who are clinically assessed as likely to benefit will continue to be referred to Bath.

CHAPTER 2: OPTIONS

How were the service options developed?

On behalf of Scottish Government and NHS Boards a group was convened to consider the provision of intensive pain management service(s) in Scotland. Membership included patients with chronic pain, third sector organisations and chronic pain clinicians. The group was asked to develop options which are broadly presented in this consultation paper.

The Scottish Government is keen to hear from people who may have other ideas that are not presented in the options. Questions have been included in the respondent form inviting further suggestions. Factors are also set out after the options that may help you identify a preferred option.

There are some factors that are important and common to all the residential options set out. These are:

- The service would be accessible to patients in Scotland, regardless of NHS Board area, who are clinically assessed as likely to benefit. This could include remote ways of working, particularly for those living in remote and rural areas.
- Patient choice is important, therefore if individuals live near to the new service they could, if they wished, go home at night or stay with family or friends nearby. However, one of the aims of providing a service in Scotland is to reduce travelling long distances. Staying in the same place as fellow patients has been shown to be supportive and may lead to continued informal support after treatment. Therefore the offer of residential accommodation will be open to all.
- The majority of patients will still need to travel, but this will be within Scotland.
- Local chronic pain services provided by NHS Boards need to be able to support patients following the treatment provided in the residential service. This is to ensure on-going support and continued improvement.
- The service would need to demonstrate improved outcomes for patients, and monitor their experience and the views of staff.

Option 1

A centre of excellence in a single location.

This option would see a national treatment and residential service developed in a single location, with a range of staff specialising in chronic pain. Local residential accommodation would be offered to those patients who wish to stay.

Service comparison – this type of residential service is similar to those provided in;

Bath Centre for Pain Services, Bath, Somerset,

<http://www.bathcentreforpainservices.nhs.uk/>

Pain and Fatigue Management Centre at Bronllys, Wales,

<http://www.wales.nhs.uk/sites3/home.cfm?orgid=470&redirect=yes>

INPUT pain management unit, Guys and St. Thomas's, London,

<http://www.guysandstthomas.nhs.uk/our-services/pain/input/overview.aspx>

It is therefore a tested service model where improved patient experiences and clinical outcomes have been demonstrated.

Option 2

A service delivered by local chronic pain clinicians supported by other clinical advisors in another part of the country.

This option would see local skilled chronic pain teams providing the service with remote support provided by other experienced staff from, for example, a central point or hub. Remote ways of working could involve tele-health, phone and video links or other technology.

An example of what this means for a patient is they could have a consultation and assessment in their local area with their own clinician(s) but also involve other clinical advisors using technology (i.e. tele-health or videoconferencing) but the clinical advisor would be in another part of the country.

The clinical advisor would then work with and support the local team. The actual treatment on a day to day basis over a 2 – 4 week period would be provided by the local team. Local residential accommodation would be offered to patients who wish to stay. This could apply throughout Scotland.

This sort of service would be supported by staff who would collect information about the service, including patient experience and clinical outcomes.

Similar service models are used for other chronic health conditions which need a very specialised service and access to additional advice. These have shown improvements in patient experience and clinical outcomes and therefore this is a tested model.

Option 3

A service delivered in different locations by a team of chronic pain specialists (an outreach or roving service).

This service would be provided by a specialist chronic pain team who would go to different parts of the country.

The team would be organised and managed by one NHS Board but travel to other health board areas to carry out assessment clinics. They would then work with and support local teams to deliver the treatment daily over a 2 – 4 week period.

Local residential accommodation would be offered to those patients who wish to stay.

Service comparison – this model is not yet tested in the NHS in Scotland. So, at this consultation stage it is not known if it is viable. It is likely that for this option it would be difficult to recruit and retain staff as they would need to be away from home for 2 – 4 weeks to deliver the service. Other services which are provided on an outreach basis tend to only have outpatient or day case appointments and do not have residential accommodation. However, this is included as we are keen to hear your views.

Factors you might want to consider in identifying a preferred option

You may find it helpful to consider the following factors when responding to the consultation, as well as any other issues not listed which are important to you.

- A service that can bring together patients with similar characteristics for example, underlying condition or age.
- A service that can offer peer support.
- A service where peer support is more likely to be sustained after the treatment is complete.
- A service that can bring together the range of clinical staff.
- A service that can offer a range of treatments and tailored programmes.
- A service that staff want to work in and can be retained in.
- A service that could provide the opportunity to train and support healthcare professionals working in local chronic pain services.
- A service that could support research work.
- A service that makes best use of technology to improve access.

CHAPTER 3: CONSULTATION QUESTIONS

Question 1: We would like to know in what context you are responding.

Question 2: Please choose your preferred option (Chapter 2 provides details).

Question 3: Are there any of the options you disagree with?

Question 4: If you have other ideas that have not been covered, please tell us about these in the comments box below. You may want to include the advantages and disadvantages of each.

Question 5: What do you think the barriers are to accessing a residential pain management service? (For example, distance away from family, work or family commitments, upfront travel costs.)

Question 6: Please choose from the list below which aspects of residential pain management services should be included in a Scottish service.

Question 7: Irrespective of the final service model selected, should access to the current service provided in Bath (or elsewhere in the UK) be retained for occasional use?

Question 8: Have you previously attended, or supported someone attending a residential service outside Scotland?

Question 9: If you have attended, or supported someone attending a residential service outside Scotland, please tell us about any advantages and disadvantages of the experience.

Question 10: If you, or someone close to you, has been offered but declined a residential service outside Scotland what were the reasons for this?

Question 11: If you wish to add any further comments on issues raised in the consultation paper or current chronic pain services in Scotland, please use the comments box below.

CHAPTER 4: HOW TO RESPOND

The Scottish Government are inviting responses to this consultation paper by 27 October 2013.

Please send your completed Respondent Information Form and completed questions to: specialistpainservices@scotland.gsi.gov.uk or to Gill Gunn, The Scottish Government, Clinical Priorities Team, Area GER, St Andrews House, Regent Road, Edinburgh, EH1 3DG.

Handling your response

The Scottish Government need to know how you wish your response to be handled and, in particular, whether you are happy for your response to be made public.

Please complete and return the Respondent Information Form as this will ensure that the Scottish Government treat your response appropriately. If you ask for your response not to be published, the Scottish Government will regard it as confidential and treat it accordingly.

All respondents should be aware that the Scottish Government is subject to the provisions of the Freedom of Information (Scotland) Act 2002, and would therefore have to consider any request made to it under the Act for information relating to responses made to this consultation exercise.

Next steps in the process

Where respondents have given permission for their response to be made public and after the Scottish Government have checked that they contain no potentially defamatory material, responses will be made available to the public in the Scottish Government Library and will also be published on the Scottish Government consultation web pages.

You can make arrangements to view responses by contacting the Scottish Government Library on 0131 244 4556. Responses can be copied and sent to you, but a charge may be made for this service.

What happens next?

Following the closing date, all responses will be analysed and a report compiled of the findings. It is anticipated an announcement on the chosen option will then be made by the Cabinet Secretary for Health and Wellbeing in January 2014. The relevant impact assessments, set out in Annex C will be undertaken as part of the next steps and an implementation plan developed.

Comments and complaints

If you have any comments about how this consultation exercise has been conducted, please send them to the Scottish Government at the address noted at the top of this page.

ANNEX A – RESPONDENT INFORMATION FORM



A consultation on the provision of specialist residential chronic pain services in Scotland

RESPONDENT INFORMATION FORM

Please Note this form **must** be returned with your response to ensure that we handle your response appropriately

1. Name/Organisation

Organisation Name

Title Mr Ms Mrs Miss Dr Please tick as appropriate

Surname

Forename

2. Postal Address

<input type="text"/>		
Postcode	Phone	Email

3. Permissions - I am responding as...

Individual	/	Group/Organisation
<input type="checkbox"/>	Please tick as appropriate	<input type="checkbox"/>

(a) Do you agree to your response being made available to the public (in Scottish Government library and/or on the Scottish Government web site)?

Please tick as appropriate

Yes No

(b) Where confidentiality is not requested, we will make your responses available to the public on the following basis

Please tick **ONE** of the following boxes

(c) The name and address of your organisation **will be** made available to the public (in the Scottish Government library and/or on the Scottish Government web site).

Are you content for your **response** to be made available?

Please tick as appropriate

Yes No

Yes, make my response, name and address all available

or

Yes, make my response available, but not my name and address

or

Yes, make my response and name available, but not my address

(d) We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for Scottish Government to contact you again in relation to this consultation exercise?

Please tick as appropriate

Yes

No

Consultation response

Question 1: We would like to know in what context you are responding. Please choose one of the following:

I am responding as:

- a) an individual who experiences chronic pain
- b) a family member or carer of someone who experiences chronic pain
- c) a health professional
- d) an organisation representing people who experience chronic pain
- e) other stakeholder (please tell us in the comments box below)

Comments (box expands with text input - there is no word limit)

Question 2: Please choose your preferred option (Chapter 2 provides details).

- Option 1 – a centre of excellence in a single location
- Option 2 – a service delivered by local chronic pain clinicians
(supported by other clinical advisors in another part of the country)
- Option 3 – a service delivered in different locations
(by a team of chronic pain specialists – an outreach or roving service)

Please tell us why this is your preferred option in the comments box below. The factors listed in Chapter 2 of the consultation paper may help you.

Comments (box expands with text input - there is no word limit)

Question 3: Are there any of the options you disagree with? (If No, move straight to Question 4.)

If yes, please tell us which one(s) in the comments box, and why?

Comments (box expands with text input - there is no word limit)

Question 4: If you have other ideas that have not been covered, please tell us about these in the comments box below. You may want to include the advantages and disadvantages of each.

Comments (box expands with text input - there is no word limit)

Question 5: What do you think the barriers are to accessing a residential pain management service? (For example, distance away from family, work or family commitments, upfront travel costs.)

Please list as many as you wish in the comments box below and include any others that are important to you.

Comments (box expands with text input - there is no word limit)

Question 6: Please choose from the list below which aspects of residential pain management services should be included in a Scottish service.

(choose as many as apply)

A chronic pain assessment

Supported one to one sessions to teach coping skills

Group sessions

Residential accommodation

Opportunity for immediate carer/support provider to accompany patient

Peer support

Tailored exercise programme

Medication assessment

Other (please tell us in the comments box below)

Comments (box expands with text input - there is no word limit)

Question 7: Irrespective of the final service model selected, should access to the current service provided in Bath (or elsewhere in the UK) be retained for occasional use?

Yes No Don't Know

Question 8: Have you previously attended, or supported someone attending a residential service outside Scotland?

Yes (please answer Question 9)

No (please move straight to Question 10)

Question 9: If you have attended, or supported someone attending a residential service outside Scotland, please tell us about any advantages and disadvantages of the experience.

Comments (box expands with text input - there is no word limit)

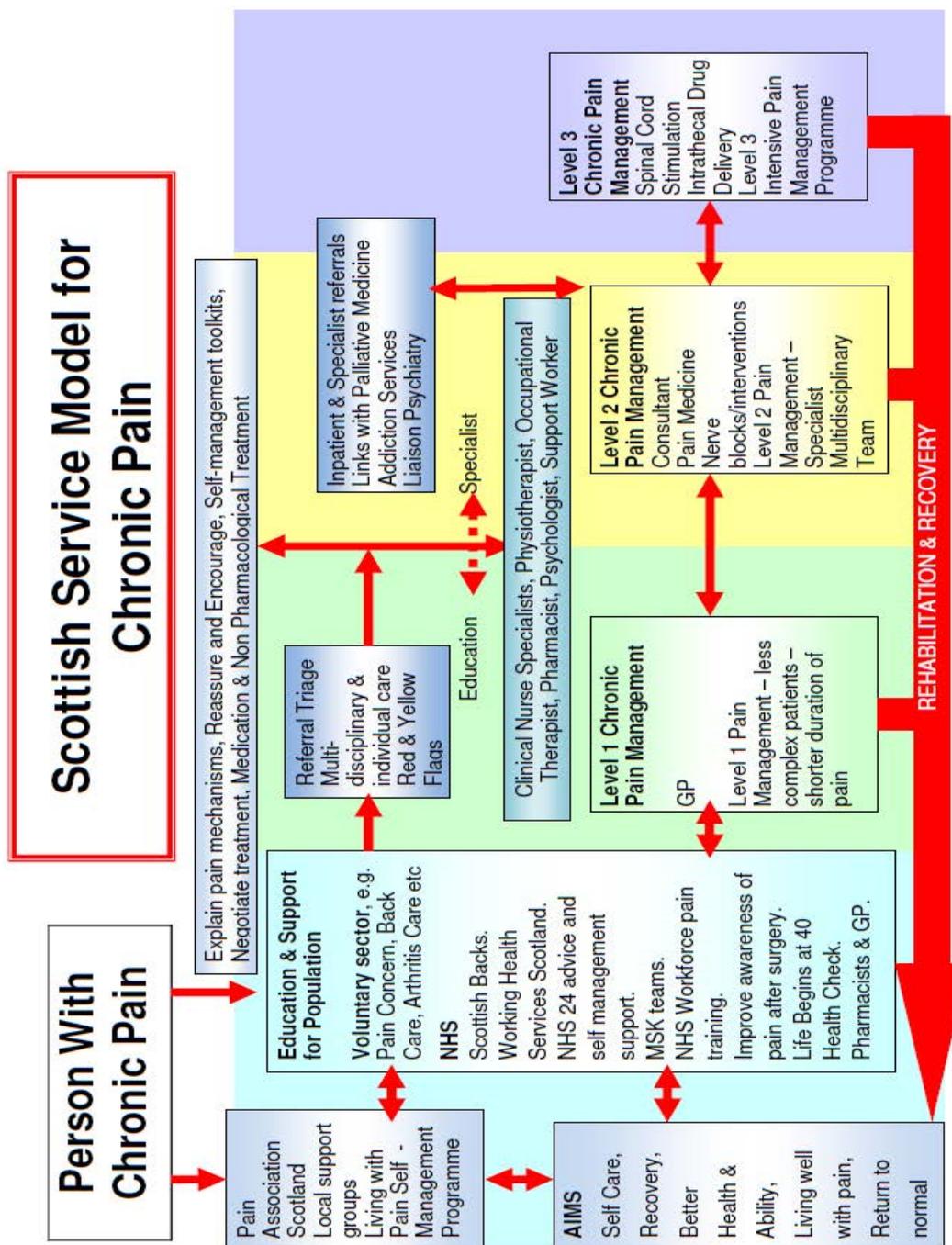
Question 10: If you, or someone close to you, has been offered but declined a residential service outside Scotland what were the reasons for this?

Comments (box expands with text input - there is no word limit)

Question 11: If you wish to add any further comments on issues raised in the consultation paper or current chronic pain services in Scotland, please use the comments box below.

Comments (box expands with text input - there is no word limit)

ANNEX B - SCOTTISH SERVICE MODEL FOR CHRONIC PAIN



Stephen Gilbert Nov 2012

ANNEX C - EQUALITY IMPACT and BUSINESS REGULATORY IMPACT ASSESSMENT INFORMATION

Equality Impact Assessment Information

The public sector equality duties require the Scottish Government to pay "due regard" to the need to:

- eliminate discrimination, victimisation, harassment or other unlawful conduct that is prohibited under the Equality Act 2010;
- advance equality of opportunity between people who share a protected characteristic and those who do not;
- foster good relations between people who share a relevant protected characteristic.

These three requirements apply across the "protected characteristics" of age; disability; gender reassignment; pregnancy and maternity; race; religion and belief; sex and sexual orientation.

In effect, this means that equality considerations are integrated into all functions and policies of Scottish Government Directorates and Agencies.

A key part of these duties is to assess the impact of all of our policies to ensure that the Scottish Government do not inadvertently create a negative impact for equality groups, and also to ensure that the Scottish Government actively seek the opportunity to promote equality of opportunity and to foster good relations.

Business Regulatory Impact Assessment Information

The Scottish Government welcomes your feedback regarding the equalities impact of the proposals presented in this paper, and the effect they may have on different sectors of the population.

The Scottish Government is committed to consulting with all parties potentially affected by proposals for new legislation, or where any regulation is being changed significantly. All policy changes, whether European or domestic, which may have an impact upon business or the third sector organisations should be accompanied by a Business Regulatory Impact Assessment (BRIA).

The BRIA helps policy makers to use available evidence to find proposals that best achieve the policy objectives, whilst minimising costs and burdens. Through consultation and engagement with business, the costs and benefits of the proposed legislation can be analysed. It also ensures that any impact on business, particularly small enterprises, is fully considered before regulations are made.

The Scottish Government welcomes your views regarding the impact that the proposals presented in this paper may have on businesses.



**The Scottish
Government**
Riaghaltas na h-Alba

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