

Mandatory Registration of Automated External Defibrillators (Scotland) Bill

A proposal for a Bill to require the registration of existing and newly acquired automated external defibrillators (AEDs) in Scotland.



**Consultation by
Anas Sarwar, MSP for Glasgow Region**

Date
3rd March 2020

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FOREWORD BY ANAS SARWAR MSP



There are around 3,500 out-of-hospital cardiac arrests in Scotland every year where resuscitation is attempted. Sadly, in only 1 in 12 of those cases will the person survive. This bill intends to provide the means to transform those numbers and dramatically improve survival rates.

Automated external defibrillators (AEDs; sometimes also referred to as public access defibrillators, or PADs) play a vital role in the 'Chain of Survival' which is the optimal method for maximising an out-of-hospital cardiac arrest patient's chances of survival. The 'Chain of Survival' includes early recognition of an out-of-hospital cardiac arrest and calling for help, early CPR, early defibrillation using an AED, and post-resuscitation care.

Defibrillation within 3–5 minutes of collapse can produce survival rates as high as 50–70%. This can be achieved through public access defibrillation, when a bystander uses a nearby AED to deliver the first shock. Each minute of delay to defibrillation reduces the probability of survival to hospital discharge by 10%. In the UK, fewer than 2% of victims have an AED deployed before the ambulance arrives.

The Scottish Ambulance Service encourages all AEDs to be registered via The Circuit, a national defibrillator network created in partnership with the British Heart Foundation and Microsoft, which can be accessed here: <https://www.thecircuit.uk/>. Registration has the advantage of allowing the ambulance service to identify the nearest AED to the location of an out-of-hospital cardiac arrest.

There is currently no legal requirement for AEDs to be registered, and studies have shown that many often go unregistered.

This can mean that the ambulance service directs a bystander to a more remote registered AED because it is unaware of a nearer, unregistered, one; or that the ambulance service cannot direct the bystander to any AED in the vicinity because the only ones nearby are unregistered.

I am therefore proposing a Member's Bill in the Scottish Parliament which would introduce a legal requirement for all AEDs accessible to the public to be registered with the Scottish Ambulance Service.

This would support the ambulance service to identify the nearest available working AED to the location of an out-of-hospital cardiac arrest, potentially significantly reducing the time involved in getting an AED to the scene and, in turn, improving survival rates.

My Member's Bill would also have the advantage of allowing for Automated External Defibrillators to be placed in a more strategic way than at present across Scotland. By locating and mapping current AEDs, we can identify areas which lack AEDs within an accessible distance, and, conversely, identify areas which already have a high concentration of AEDs and where adding more would be of limited value. This will enable those considering purchasing an AED to make better-informed decisions about whether to do so and where to locate them.

I want Scotland to lead the way in out-of-hospital cardiac arrest survival, and my proposed Member's Bill supports that ambition.

Anas Sarwar MSP

HOW THE CONSULTATION PROCESS WORKS

This consultation relates to a draft proposal I have lodged as the first stage in the process of introducing a Member's Bill in the Scottish Parliament. The process is governed by Chapter 9, Rule 9.14, of the Parliament's Standing Orders which can be found on the Parliament's website at:

<https://parliament.scot/parliamentarybusiness/17797.aspx>

At the end of the consultation period, all the responses will be analysed. I would then have the option of lodging a final proposal in the Parliament along with a summary of those responses. If that final proposal secure the support of at least 18 other MSPs from at least half of the political parties or groups represented in the Parliamentary Bureau, and the Scottish Government did not indicate that it intended to legislate in the area in question, I would then have the right to introduce a Member's Bill. However, I recognise that it will not be possible to introduce such a Bill in the current Parliamentary session, since the deadline for introducing any remaining Members' Bills is 1 June 2020. Instead, I am launching this consultation with a view to introducing a Bill early in the next session (beginning in May 2021) should I be re-elected.

The purpose of this consultation is to provide a range of views on the subject matter of the proposed Bill, highlighting potential problems, suggesting improvements, and generally refining and developing the policy. Consultation, when done well, can play an important part in ensuring that legislation is fit for purpose.

The consultation process is being supported by the Scottish Parliament's Non-Government Bills Unit (NGBU) and will therefore comply with the Unit's good practice criteria. NGBU will also analyse and provide an impartial summary of the responses received.

Details on how to respond to this consultation are provided at the end of the document.

Additional copies of this paper can be requested by contacting me at (MSP's Parliamentary address, telephone number and email address).

Enquiries about obtaining the consultation document in any language other than English or in alternative formats should also be sent to me.

An on-line copy is available on the Scottish Parliament's website (www.parliament.scot) under Parliamentary Business / Bills / Proposals for Members' Bills.

AIM OF THE PROPOSED BILL

Automated external defibrillators (AEDs) allow the delivery of an electric shock to out-of-hospital cardiac arrest (OHCA) patients. They are easy to use, accurate and can be used safely and effectively by those with no prior training.¹

AEDs increase the likelihood of survival in out-of-hospital cardiac arrest (OHCA) patients. Each minute of delay to defibrillation, which is the delivery of an electric shock to restore normal heartbeat, reduces the probability of survival to hospital discharge by 10%.² Prompt defibrillation is vital for ensuring good patient outcomes from OHCA.

This Bill would place a duty on the purchaser or guardian of all existing and newly-purchased AEDs in Scotland to register it with the Scottish Ambulance Service, supporting the ambition of prompt identification and deployment of more AEDs in incidences of OHCA, with the result an increased likelihood of survival.

BACKGROUND

International evidence shows that AEDs are used in only a small number of bystander-witnessed out-of-hospital cardiac arrests (OHCAs), often in less than 5% of cases,³ with UK estimates showing AED use in as little as 2% of cases,⁴ the body of evidence points to a number of different factors, including the low level of registration of AEDs, which can often mean that emergency medical dispatchers are unaware of where AEDs are located and therefore unable to promptly direct bystanders to use them.

The mandatory registration of all public AEDs would be a significant step in improving the ability of the Scottish Ambulance Service to direct a bystander to the nearest AED, by giving it access to a greater pool of AEDs across the country.

Research demonstrates that AEDs can have a significant impact on survival outcomes. Population survival rates from OHCA in the UK are around 1 in 10, while reported rates in other countries vary from some as low as 2% and others as high as 11%. However,

¹ Smith CM et al (2017) *Barriers and facilitators to public access defibrillation in out-of-hospital cardiac arrest: A systematic review*, European heart journal quality of care & clinical outcomes, 3(4): 264-73.

² Adult basic life support and automated external defibrillation; Resuscitation Council (UK); accessed via: <https://www.resus.org.uk/resuscitation-guidelines/adult-basic-life-support-and-automated-external-defibrillation/>.

³ Warwick Clinical Trials Unit, Out-of-Hospital Cardiac Arrest Outcomes Registry, Epidemiology Report 2017, available at: <https://warwick.ac.uk/fac/sci/med/research/ctu/trials/ohcao/publications/epidemiologyreports/>.

⁴ Deakin CD, Shewry E, Gray HH. Public access defibrillation remains out of reach for most victims of out-of-hospital sudden cardiac arrest. Heart 2014;100:619-23.

survival rates as high as 70% have been reported in victims of OHCA from a cardiac cause who were defibrillated within two minutes of the initial collapse.⁵

Data relating to the number of cases where emergency medical dispatchers have directed someone to the nearest AED and how often AEDs are used in OHCA cases is not publicly available in Scotland. However, research carried out in Sweden found that an AED was 15 times more likely to be used if it was registered with the local AED registry. Therefore, should the Scottish Ambulance Service have an awareness of where all AEDs are located in the country, this could have a significant impact upon AED usage rates in the country. In addition, we are keen to explore whether certain buildings or venues should be required to have available an AED e.g. theatres and shopping centres.

Currently in Scotland there is no legislation governing the registration of AEDs and the purchaser / guardian of an AED is invited to register it with the Scottish Ambulance Service on a voluntary basis. This can often mean that out-of-hospital cardiac arrests occur in the vicinity of an AED which is unknown to the Scottish Ambulance service, meaning that bystanders are unable to be directed to these AEDs and use them to deliver crucial and potentially lifesaving defibrillation to the OHCA patient. International evidence from Sweden and the USA shows that in many places the majority of nearby AEDs are unknown to ambulance services.⁶

The proposed bill would place a duty on vendors, purchasers and/or guardians of AEDs to ensure that they are registered, as soon as feasibly possible following their purchase, with the Scottish Ambulance Service. This would have the aim of ensuring the maximum number of AEDs possible are registered with the Scottish Ambulance Service, allowing bystanders to be directed to them in the event of an OHCA and to draw on their lifesaving potential to provide OHCA patients the greatest possible chance of survival.

Current legal/legislative context

At present in Scotland, the registration of AEDs operates on a voluntary basis, and there is no legislative mechanism compelling purchasers or guardians to register them.

AEDs can be registered with the Scottish Ambulance Service via The Circuit, at www.thecircuit.uk.

⁵ Smith, C, et al. (2017), *Barriers and facilitators to public access defibrillation in out-of-hospital cardiac arrest: a systematic review*, European Heart Journal - Quality of Care and Clinical Outcomes 3, 264-273.

⁶ Smith, C, et al. (2017), *Barriers and facilitators to public access defibrillation in out-of-hospital cardiac arrest: a systematic review*, European Heart Journal - Quality of Care and Clinical Outcomes 3, 264-273.

In June 2018, 1,889 AEDs were registered with the Scottish Ambulance Service⁷. Data on the rate of AED usage in Scotland is not currently gathered.

International examples

A study carried out in Stockholm found that an AED was 15 times more likely to be used if registered with the SALSA (Saving Lives in the Stockholm Area) project than if the AED was not registered.⁸

Smith et al (2017) identified seven observational studies, three simulation randomized controlled trials (RCTs) and one other simulation study focussed on the use of AEDs by people being talked through the process remotely by emergency medical services staff (known as EMS dispatch-assisted AED use).

Simulated OHCA scenarios have demonstrated that EMS dispatch assistance resulted in a shorter time to AED retrieval and defibrillation in 62% of cases, and in correct use of an AED in 79% of cases. In a simulation RCT of adults over 75 years of age, those receiving EMS assistance over the telephone were more likely than those who received no assistance to correctly deliver an AED shock (91% vs 68%).⁹

We know from international analysis that in a significant number OHCA incidents where AEDs are used, the AEDs are unregistered and the EMS are unaware of their location. In Stockholm (2006–2012), 72% of cases of public-access AED use involved the use of AEDs not previously known to the city's Public Access Defibrillation (PAD) programme.⁸ In Washington state (2007–2009), 59% of cases of public-access AED use involved the use of AEDs not known to EMS.⁸⁰ In a mixed-method study to identify the locations of as many AEDs as possible in North Carolina (2001–2002), only 18% were already known to EMS.¹⁰

In a controlled study in the region of Gotland in Sweden, it was found that more than 50% of AEDs were non-registered, a figure which is in line with national Swedish estimates.¹¹

⁷ Response to Parliamentary Question S50-02297 provided by then Minister for Public Health on 28 June 2018, available at <https://www.parliament.scot/parliamentarybusiness/28877.aspx?SearchType=Advance&ReferenceNumbers=S50-02297&ResultsPerPage=10>.

⁸ Ringh, M. et al (2015) *Survival after Public Access Defibrillation in Stockholm, Sweden – A striking success*, Resuscitation 91 (2015) 1-7.

⁹ Smith, CM et al (2017), *Barriers and facilitators to public access defibrillation in out-of-hospital cardiac arrest: a systematic review*, European Heart Journal - Quality of Care & Clinical Outcomes, Volume 3, Issue 4, October 2017, Pages 264-273.

¹⁰ Smith, CM et al (2017), *Barriers and facilitators to public access defibrillation in out-of-hospital cardiac arrest: a systematic review*, European Heart Journal - Quality of Care & Clinical Outcomes, Volume 3, Issue 4, October 2017, Pages 264-273.

¹¹ Ibid.

There may be barriers to AED registration and we are keen to explore why this is the case.

A survey conducted among owners of AEDs in Sweden found the most common reason for non-registration was not being aware that this was an option (74.5%). Among owners who were aware of the option but did not register their AEDs, the most common reasons for not registering were: a perception that the AED would be “hard to register” (25%), not wanting the AED to be visible (12.5%), not wanting the AED to be dispatched by Emergency Medical Services, and the risk of theft (4.2%).¹² It would therefore be important for the public to have an awareness of the AED registration system and it is proposed that this Bill would place a duty on the Scottish Government to publicise the registration system. It would also be vital to ensure that the registration system is as simple and user-friendly as possible to avoid potentially deterring guardians from either not initiating or completing the registration process.

DETAIL OF THE PROPOSED BILL

This Bill would place a duty on the purchaser or guardian and/or the vendor of every AED in Scotland to register it with the Scottish Ambulance Service, supporting the ambition of permitting the prompt identification and deployment of more AEDs in incidences of OHCA.

Preference is given to the registration of all AEDs; however, the consultation includes a question regarding alternatives to this proposal, such as whether the duty to register AEDs should be limited to public bodies and not all AED purchasers and/or guardians.

The proposed legislation would not require organisations or places of business to amend their hours of operation or placement of any current AEDs to allow permanent access. Organisations and places of businesses with fixed opening hours could provide this information at the point of registration so that the Scottish Ambulance Service is aware that any potential AED may not be accessible, for example, during evenings or weekends, allowing the Scottish Ambulance Service to direct a bystander instead to the second-closest AED in the event of a nearby OHCA.

The Bill will primarily have an impact on three distinct groups. Firstly, those selling and/or purchasing AEDs will be expected to register it as soon as feasibly possible following its sale and anyone who already owns or is responsible for an AED will be expected to register it as soon as feasibly possible after the new legislation comes into force Secondly, it is anticipated that the Bill will provide the Scottish Ambulance Service with an increased awareness of the actual number of AEDs in Scotland and their precise location, allowing them to signpost the nearest AED to the person calling 999 in the event of an OHCA. Thirdly, it is expected that the Bill would provide increased

¹² Ibid.

access to AEDs for bystanders and allow them to be accessed within shorter timeframes than at present, increasing the probability of the OHCA patient achieving neurologically-intact survival.

Respondents' views are sought on whether all newly-purchased and existing AEDs should require to be registered with The Scottish Ambulance Service.

The consultation also seeks respondents' views on whether responsibility for registering a new AED should lie with the person purchasing the AED, the person selling it, or another person (or some combination of the three).

The consultation is also seeking views on whether sanctions, if any, should be applied in the event of failure to register. We recognise this may well require further, and more detailed, consideration, but the views of respondents on the principle of whether sanctions should be considered is sought.

It would also be vital for the Scottish Ambulance Service to have an accurate and up-to-date record of all functioning and accessible AEDs. With that in mind, respondents' views are sought on whether the proposed Bill should place a duty on the Scottish Ambulance Service to verify that all registered AEDs remain in place and are accessible, and the frequency with which this verification process should be carried out.

The main benefits which it is expected this Bill would bring about would be in terms of the number of lives saved from out-of-hospital cardiac arrests due to the Scottish Ambulance Service being able to direct bystanders to nearby AEDs more efficiently and effectively.

FINANCIAL IMPLICATIONS

There is no cost involved in the current AED registration process through the Scottish Ambulance Service's website. The Bill would not seek to amend this process and would seek to maintain it as a free registration service. The registration portal can be accessed provided the AED purchaser, guardian or vendor is able to access the internet.

The Bill also would not seek to place a duty on businesses, organisations or individuals to make any existing or future AEDs permanently accessible. Such businesses and organisations with fixed hours of operation would provide details of the hours of accessibility of its AED to the Scottish Ambulance Service, which would allow for the signposting of the second-closest AED, should an OHCA occur nearby outside of the business or organisations' hours of operation.

It is therefore anticipated that the financial implications of this Bill would be minimal.

EQUALITIES AND SUSTAINABILITY IMPACTS

It is not anticipated that this Bill will have create any specific impact on equalities or sustainable development.

QUESTIONS

ABOUT YOU

(Note: Information entered in this “About You” section may be published with your response (unless it is “not for publication”), except where indicated in **bold**.)

1. Are you responding as:

- an individual – in which case go to Q2A
- on behalf of an organisation? – in which case go to Q2B

2A. Which of the following best describes you? (If you are a professional or academic, but not in a subject relevant to the consultation, please choose “Member of the public”.)

- Politician (MSP/MP/peer/MEP/Councillor)
- Professional with experience in a relevant subject
- Academic with expertise in a relevant subject
- Member of the public

Optional: You may wish to explain briefly what expertise or experience you have that is relevant to the subject-matter of the consultation:

2B. Please select the category which best describes your organisation:

- Public sector body (Scottish/UK Government or agency, local authority, NDPB)
- Commercial organisation (company, business)
- Representative organisation (trade union, professional association)
- Third sector (charitable, campaigning, social enterprise, voluntary, non-profit)
- Other (e.g. clubs, local groups, groups of individuals, etc.)

Optional: You may wish to explain briefly what the organisation does, its experience and expertise in the subject-matter of the consultation, and how the view expressed in the response was arrived at (e.g. whether it is the view of particular office-holders or has been approved by the membership as a whole).

3. Please choose one of the following:

- I am content for this response to be published and attributed to me or my organisation

- I would like this response to be published anonymously
- I would like this response to be considered, but not published (“not for publication”)

If you have requested anonymity or asked for your response not to be published, please give a reason. **(Note: your reason will not be published.)**

4. Please provide your name or the name of your organisation. **(Note: The name will not be published if you have asked for the response to be anonymous or “not for publication”.)**

Name:

Please provide a way in which we can contact you if there are queries regarding your response. Email is preferred but you can also provide a postal address or phone number. **(Note: We will not publish these contact details.)**

Contact details:

5. Data protection declaration

- I confirm that I have read and understood the privacy notice attached to this consultation which explains how my personal data will be used.

YOUR VIEWS ON THE PROPOSAL

Note: All answers to the questions in this section may be published (unless your response is “not for publication”).

Aim and approach

1. Which of the following best expresses your view of making it a legal requirement to register every Automated External Defibrillator with The Scottish Ambulance Service?

- Fully supportive
- Partially supportive
- Neutral (neither support nor oppose)
- Partially opposed
- Fully opposed
- Unsure

Please explain the reasons for your response.

2. What do you think would be the main practical advantages and disadvantages of the proposed Bill?

3. What impact would you expect a legal duty to register Automated External Defibrillators with the Scottish Ambulance Service to have on out-of-hospital cardiac arrest survival rates in Scotland?

- Improved survival rates
- Slightly improved survival rates
- Neither improved nor worsened survival rates
- Slightly worsened survival rates
- Considerably worsened survival rates
- Unsure

Please explain the reasons for your response.

4. Do you consider that the proposed Bill should place a duty on the Scottish Ambulance Service or NHS Scotland to verify at regular intervals whether registered Automated External Defibrillators remain in place and are accessible?

- Yes – once every 6 months
- Yes – once every year
- Yes – once every 5 years
- Yes – at another interval (please specify)
- No
- Unsure

Please explain the reasons for your response.

5. Who should be legally required to register a newly-purchased Automated External Defibrillator? Please choose all that apply.

- The purchaser
- The vendor
- Someone other than the purchaser or vendor (please specify)
- None of the above
- Unsure

Please explain the reasons for your response.

6. Should the legal requirement to register Automated External Defibrillators be limited to AEDs owned by (or held on the premises of) public bodies?

- Yes
- No
- Unsure

Please explain the reasons for your response.

7. Do you consider there should be any sanction for failure to comply with the mandatory registration?

- Yes
- No
- Unsure

Please explain the reasons for your response. If you answered yes, what should the sanction be?

8. If you are the guardian of an Automated External Defibrillator which has already been registered, please tell us how you found the registration process.

If it has not been registered, what were the reason(s) for not registering it?

Financial implications

9. Taking account of both costs and potential savings, what financial impact would you expect the proposed Bill to have on:

(a) Government and the public sector (including the NHS and the Scottish Ambulance Service)

- Significant increase in cost

- Some increase in cost
- Broadly cost-neutral
- Some reduction in cost
- Significant reduction in cost
- Unsure

(b) Businesses (including those making or selling AEDs and those with AEDs on their premises)

- Significant increase in cost
- Some increase in cost
- Broadly cost-neutral
- Some reduction in cost
- Significant reduction in cost
- Unsure

(b) Individuals (including those owning or responsible for AEDs)

- Significant increase in cost
- Some increase in cost
- Broadly cost-neutral
- Some reduction in cost
- Significant reduction in cost
- Unsure

Please explain the reasons for your response.

10. Are there ways in which the Bill could achieve its aim more cost-effectively?

Equalities

11. What overall impact is the proposed Bill likely to have on equality, taking account of the following protected characteristics (under the Equality Act 2010): age,

disability, gender re-assignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, sexual orientation?

- Positive
- Slightly positive
- Neutral (neither positive nor negative)
- Slightly negative
- Negative
- Unsure

Please explain the reasons for your response.

Sustainability

12. Do you consider that the proposed bill can be delivered sustainably, i.e. without having likely future disproportionate economic, social and/or environmental impacts?

- Yes
- No
- Unsure

Please explain the reasons for your response.

General

14. Do you have any other comments or suggestions on the proposal?

HOW TO RESPOND TO THIS CONSULTATION

You are invited to respond to this consultation by answering the questions in the consultation and by adding any other comments that you consider appropriate.

Format of responses

You are encouraged to submit your response via an online survey (Smart Survey) if possible, as this is quicker and more efficient both for you and the Parliament. However, if you do not have online access, or prefer not to use Smart Survey, you may also respond by e-mail or in hard copy.

Online survey

To respond via online survey, please follow this link:

<https://www.smartsurvey.co.uk/s/Defibrillators/>

The platform for the online survey is Smart Survey, a third party online survey system enabling the SPCB to collect responses to MSP consultations. Smart Survey is based in the UK and is subject to the requirements of the General Data Protection Regulation (GDPR) and any other applicable data protection legislation. Any information you send in response to this consultation (including personal data) will be seen by the MSP progressing the Bill and by staff in NGBU.

Further information on the handling of your data can be found in the Privacy Notice, which is available either via the Smart Survey link above, or at the end of this document.

Smart Survey's privacy policy is available here:

<https://www.smartsurvey.co.uk/privacy-policy>

Electronic or hard copy submissions

Responses not made via Smart Survey should, if possible, be prepared electronically (preferably in MS Word). Please keep formatting of this document to a minimum. Please send the document by e-mail (as an attachment, rather than in the body of the e-mail) to:

Anas.Sarwar.msp@parliament.scot

Responses prepared in hard copy should either be scanned and sent as an attachment to the above e-mail address or sent by post to:

Anas Sarwar MSP
Scottish Parliament
Edinburgh EH99 1SP

Responses submitted by e-mail or hard copy may be entered into Smart Survey by my office or by NGBU.

If submitting a response by e-mail or hard copy, please include written confirmation that you have read and understood the Privacy Notice (set out below).

You may also contact my office by telephone on **0141 465 9933**.

Deadline for responses

All responses should be received no later than **25th May 2020**. Please let me know in advance of this deadline if you anticipate difficulties meeting it. Responses received after the consultation has closed will not be included in any summary of responses that is prepared.

How responses are handled

To help inform debate on the matters covered by this consultation and in the interests of openness, please be aware that I would normally expect to publish all responses received (other than “not for publication” responses) on my website, www.anassarwar.co.uk. Published responses (other than anonymous responses) will include the name of the respondent, but other personal data sent with the response (including signatures, addresses and contact details) will not be published.

Where responses include content considered to be offensive, defamatory or irrelevant, my office may contact you to agree changes to the content, or may edit the content itself and publish a redacted version.

Copies of all responses will be provided to the Scottish Parliament’s Non-Government Bills Unit (NGBU), so it can prepare a summary that I may then lodge with a final proposal (the next stage in the process of securing the right to introduce a Member’s Bill). The Privacy Notice (below) explains more about how the Parliament will handle your response.

If I lodge a final proposal, I will be obliged to provide copies of responses (other than “not for publication” responses) to the Scottish Parliament’s Information Centre (SPICe). SPICe may make responses available to MSPs or staff on request.

Requests for anonymity or for responses not to be published

If you wish your response to be treated as anonymous or “not for publication”, please indicate this clearly. The Privacy Notice (below) explains how such responses will be handled.

Other exceptions to publication

Where a large number of submissions is received, particularly if they are in very similar terms, it may not be practical or appropriate to publish them all individually. One option may be to publish the text only once, together with a list of the names of those making that response.

There may also be legal reasons for not publishing some or all of a response – for example, if it contains irrelevant, offensive or defamatory content. If I think your response contains such content, it may be returned to you with an invitation to provide a justification for the content or to edit or remove it. Alternatively, I may publish it with the content edited or removed, or I may disregard the response and destroy it.

Data Protection

As an MSP, I must comply with the requirements of the General Data Protection Regulation (GDPR) and other data protection legislation which places certain obligations on me when I process personal data. As stated above, I will normally publish your response in full, together with your name, unless you request anonymity or ask for it not to be published. I will not publish your signature or personal contact information. The Privacy Notice (below) sets out in more detail what this means.

I may also edit any part of your response which I think could identify a third party, unless that person has provided consent for me to publish it. If you wish me to publish information that could identify a third party, you should obtain that person's consent in writing and include it with your submission.

If you consider that your response may raise any other issues under the GDPR or other data protection legislation and wish to discuss this further, please contact me before you submit your response. Further information about data protection can be found at: www.ico.gov.uk.

Freedom of Information (Scotland) Act 2002

As indicated above, NGBU may have access to information included in, or provided with, your response that I would not normally publish (such as confidential content, or your contact details). Any such information held by the Parliament is subject to the requirements of the FOISA. So if the information is requested by third parties the Scottish Parliament must consider the request and may have to provide the information unless the information falls within one of the exemptions set out in the Act. I cannot therefore guarantee that any such information you send me will not be made public should it be requested under FOISA.

Further information about Freedom of Information can be found at:

www.itspublicknowledge.info.

Privacy Notice

This privacy notice explains how your ***personal data** which may be included in, or is provided with, your response to a MSP's consultation on a proposal for a Member's Bill will be ****processed**. This data will include any personal data including *****special category data** that is included in responses to consultation questions, and will also include your name and your contact details provided with the response. Names and contact details fall into **normal category data**.

***Personal data** is information that relates to an identified or identifiable individual.

****Processing** of personal data refers to any operations carried out in relation to the data such as collecting, storing, sharing and deletion of the data.

*****Special category data** includes information about an individual's race; ethnic origin; political or religious views; sex life or sexual orientation; trade union membership; physical or mental health; genetic or biometric data.

Collecting and holding Personal Data

The Scottish Parliamentary Corporate Body (SPCB) processes any personal data you send to it, or that the MSP whose consultation you respond to shares with it (under a data-sharing agreement) according to the requirements of the General Data Protection Regulation (GDPR) and the Data Protection Act 2018 (DPA).

The SPCB will hold any personal data securely, will use it only for the purposes it was collected for and will only pass it to any third parties (other than the MSP whose consultation you respond to) with your consent or according to a legal obligation. Further information about data protection legislation and your rights is available here: <https://ico.org.uk/for-the-public/is-my-information-being-handled-correctly/>

Purpose of the data processing

The purpose of collecting, storing and sharing personal data contained in consultation responses is to enable Members to consider the views of respondents to inform the development of the Bill, with the support of NGBU. Personal data contained in consultation responses will not be used for any other purpose without the express consent of the data subject.

The legal basis

The legal basis for collecting, holding, sharing and publishing your personal data is that the processing is necessary for the performance of a task carried out in the public interest (for normal category data), or in the substantial public interest (for special category data), in accordance with Art 6(1)(e) GDPR and section 8(d) DPA (for normal category data), or Art 9(1)(g) GDPR and section 10 of and paragraph 6 of Schedule 1 DPA (for special category data). The task is to support Members seeking to introduce Members' Bills to the Parliament. This is a core task of the SPCB and therefore a Crown function. The adequate support of the Members Bill process and the ability to seek, use and temporarily store personal data including special category data is in the substantial public interest.

If the person responding to the consultation is under the age of 12 then consent from the parent or guardian of the young person will be required to allow the young person to participate in the consultation process (however, the legal basis for the processing of the personal data submitted remains as the public interest task basis identified above).

Sharing Personal Data

The data collected and generated by Smart Survey will be held by the Non-Government Bills Unit (NGBU), a team in the Scottish Parliament which supports MSPs progressing Members' Bills, and shared with the MSP who is progressing the Bill and staff in the MSP's office. Data submitted by other means (e.g. by email or hard copy) will be held by the MSP's office and shared with NGBU for the purposes of producing a summary of responses to the consultation. The MSP and NGBU are joint data controllers of the data. Under a data-sharing agreement between the MSP and the Scottish Parliament, access to the data is normally limited to NGBU staff working on the Member's Bill/proposal, the MSP and staff in the MSP's office working on the Member's Bill/proposal; but data may also be shared by NGBU with the Scottish Parliament's solicitors in the context of obtaining legal advice.

Publishing Personal Data

"Not for publication" responses will not be published and will only be referred to in the summary of consultation responses in the context of a reference to the number of "not for publication" responses received and, in some cases, in the context of a general reference that is considered by you to be consistent with the reasons for choosing "not for publication" status for your response.

Anonymous responses will be published without your name attached, your name will not be mentioned in the summary of consultation responses, and any quote from or reference to any of your answers or comments will not be attributed to you by name.

Other responses may be published, together with your name; and quotes from or references to any of your answers or comments, together with your name, may also be published in the summary of consultation responses.

Contact details (e.g. your e-mail address) provided with your response will not be published, but may be used by either the MSP's office or by NGBU to contact you about your response or to provide you with further information about progress with the proposed Bill.

Where personal data, whether relating to you or to anyone else, is included in that part of your response that is intended for publication, the MSP's office or NGBU may edit or remove it, or invite you to do so; but in certain circumstances the response may be published with the personal data still included.

Please note, however, that references in the foregoing paragraphs to circumstances in which responses or information will not be published are subject to the Parliament's legal obligations under the Freedom of Information (Scotland) Act 2002. Under that Act, the Parliament may be obliged to release to a requester information that it holds, which

may include personal data in your response (including if the response is “not for publication” or anonymous).

Use of Smart Survey software

The Scottish Parliament is licensed to use Smart Survey which is a third party online survey system enabling the Scottish Parliament to collect responses to MSP consultations, to extract and collate data from those responses, and to generate statistical information about those responses. Smart Survey is based in the UK and is subject to the requirements of data protection legislation.

Any information you send by email or in hard copy in response to a consultation on a proposal for a Member’s Bill may be added manually to Smart Survey by the MSP’s office or by NGBU.

The privacy policy for Smart Survey is available here:

<https://www.smartsurvey.co.uk/privacy-policy>

While the collected data is held on Smart Survey, access to it is password protected. Where the data is transferred to our own servers at the Scottish Parliament, access will be restricted to NGBU staff through the application of security caveats to all folders holding consultation data.

Access to, retention and deletion of personal data

If a summary of consultation responses is published within six months of the consultation period ending, all of your data will be deleted from Smart Survey as soon as possible after the summary is published. If, six months after the consultation period has ended, a summary has not been published, then responses may be downloaded from Smart Survey and saved (with all the information that would normally not be published – including contact details – removed) to Scottish Parliament IT systems and retained until the end of the session of the Parliament in which the consultation took place. When that is done, all responses will normally be deleted from Smart Survey; but in exceptional circumstances, your data may be retained in Smart Survey beyond the end of the six month period if that is necessary for the purpose of preparing a summary for future publication. All data will be deleted from Smart Survey at the end of the session of the Parliament during which it was collected. If the MSP lodges a final proposal, he/she is required to provide a copy of your response (unless it was “not for publication”), together with your name (unless you requested anonymity), but not your contact details, to the Scottish Parliament Information Centre (SPICe), where it will be retained permanently in line with the collection management policy.

Your rights

Data protection legislation sets out the rights which individuals have in relation to personal data held about them by data controllers. Applicable rights are listed below, although whether you will be able to exercise data subject rights in a particular case may depend on the purpose for which the data controller is processing the data and the legal basis upon which the processing takes place.

For example, the rights allowing for deletion or erasure of personal data (right to be forgotten) and data portability do not apply in cases where personal data is processed for the purpose(s) of the performance of a task carried out in the public interest. The right to object to the processing of personal data for the purpose of a public interest task is restricted if there are legitimate grounds for the processing which override the interest of the data subject. This would be considered on a case by case basis and depends on what personal data is involved and the risks further processing of that data would pose to you.

The following rights will apply:

Access to your information – You have the right to request a copy of the personal information about you that we hold.

Correcting your information – We want to make sure that your personal information is accurate, complete and up to date and you may ask us to correct any personal information about you that you believe does not meet these standards.

Objecting to how we may use your information – Where we use your personal information to perform tasks carried out in the public interest then, if you ask us to, we will stop using that personal information unless there are overriding legitimate grounds to continue.

Restricting how we may use your information – in some cases, you may ask us to restrict how we use your personal information. This right might apply, for example, where we are checking the accuracy of personal information about you that we hold or assessing the validity of any objection you have made to our use of your information. The right might also apply where this is no longer a basis for using your personal information but you don't want us to delete the data. Where this right is validly exercised, we may only use the relevant personal information with your consent, for legal claims or where there are other public interest grounds to do so.

Please contact us in any of the ways set out in the *Contact information and further advice* section if you wish to exercise any of these rights.

Changes to our privacy notice

We keep this privacy notice under regular review and will place any updates on this website. Paper copies of the privacy notice may also be obtained using the contact information below.

This privacy statement was last updated on **24 October 2019** and will be reviewed within 12 months if not updated prior to that.

Contact information and further advice

If you have any further questions about the way in which we process personal data, or about how to exercise your rights, please contact:

The Head of Information Governance
The Scottish Parliament
Edinburgh
EH99 1SP

Telephone: 0131 348 6913 (Text Relay calls welcome)
Textphone: 0800 092 7100
Email: dataprotection@parliament.scot

Complaints

We seek to resolve directly all complaints about how we handle personal information, but you also have the right to lodge a complaint with the Information Commissioner's Office: <https://ico.org.uk/make-a-complaint/>

By phone: 0303 123 1113

Please contact us if you require information in another language or format.