Executive summary

Introduction
1. Between 7 December 2016 and 14 March 2017, the Scottish Government undertook a public consultation inviting views on ways of increasing the numbers of successful organ and tissue donations. The consultation paper outlined current procedures regarding organ and tissue donation, and options for increasing donations including, potentially, the introduction of an opt out / deemed authorisation system (i.e. where organs and tissue can be taken for transplantation unless people have made it clear they do not wish this to happen after their death). It also suggested possible ways of increasing referrals by clinical teams to specialist transplant teams when they are caring for a dying or recently deceased patient.

2. The consultation paper was made available on the Scottish Government’s online consultation hub and was also sent directly to relevant stakeholder groups.

3. The consultation contained 18 questions which were a mix of closed (tick-box) questions and open questions inviting further comment. Both quantitative and qualitative analyses of the responses were undertaken. The aim of the analysis was to report on responses to the consultation’s closed questions, and explore the reasons respondents gave for their answers, highlighting differences in views between different groups where appropriate. However, it should be noted that not all respondents answered all questions. Some organisational respondents, in particular, chose not to answer the closed (tick-box) questions, but provided comments on issues relevant to the question.

4. The findings presented here summarise the views of those who participated in the consultation. Given that this was a self-selected group, these findings should not be seen as representing the views of the wider population.

About the respondents
5. The consultation received 824 responses from 778 individuals and 45 organisations. In addition, one response took the form of a petition with 18,500 signatures. Organisational respondents comprised NHS and local authority bodies (including partnerships); voluntary sector agencies and charities; professional and regulatory bodies; and faith groups.

Respondents’ views on the principle of a soft opt out system (Q1)
6. Most individuals (84%) supported the principle of a soft opt out system (that is, an opt out system with additional checks built in), while organisations were divided in their views (53% in favour vs 47% opposed). Among organisations, voluntary sector groups were largely in support of the principle of a soft opt out system while faith groups were mainly opposed.

Views on improving the current opt in system (Q2)
7. Respondents were also asked for their views about changes which might be made to the current opt in system to increase the number of organs available for transplant. A wide range of suggestions were offered. These focused on: respecting donors’ wishes; developing initiatives within the health service to increase donations; taking active steps to encourage registration on the Organ Donor Register (ODR); promoting and advertising organ donation; and improving information on organ donation and transplantation. Respondents also discussed potential administrative improvements to the current system.

8. At the same time, however, some respondents thought the current system already worked well, while others thought it could not be made to work well.
Taking account of the views of family members where an individual has opted in (Q3)

9. The consultation asked for views on whether a donation should or should not proceed in a situation where families oppose a donation even though the individual has indicated their wishes to be an organ donor.

10. Most individual respondents (83%) were in favour of the donation proceeding in these circumstances, while most organisations (64%) thought that the donation should not proceed.

11. Respondents who were in favour of the donation proceeding despite family objections argued that families did not have the ‘right’ to overrule a decision taken by a potential donor, nor were they well placed to make such a decision at the time of a loved one’s death.

12. Those who thought that the donation should not go ahead if the family opposed it believed that proceeding in such circumstances would: (i) exacerbate family distress; (ii) alienate families; (iii) undermine public confidence in the health service and organ donation system; and (iv) endanger patient safety. However, within this group there was also a view that decisions in such circumstances should be taken on a case by case basis, and that sensitive efforts should be made to encourage the family to respect the donor’s wishes.

Operation of a soft opt out system (Q4)

13. The consultation paper explained that a workable soft opt out system would involve: (i) high profile awareness-raising campaigns for at least 12 months before the introduction of the new system, and on a regular basis after implementation; and (ii) upon the death of an individual in hospital, a process of undertaking a range of checks to decide whether a donation from that individual could proceed. The consultation asked for views in relation to the proposed checks.

14. In general, respondents agreed that, if an opt out system were introduced, the proposed checks set out in the consultation paper were sufficient to decide whether the donation should proceed. Two-thirds (67%) of organisational respondents and 86% of individual respondents indicated agreement. However, four out of the six faith groups thought the checks outlined were not sufficient.

15. Those who did not think the checks were sufficient were generally opposed to the principle of an opt out system and concerned about the practice of deemed authorisation. Occasionally, this group of respondents suggested additional checks that could be included and many of these focused on a situation in which an individual’s family / friends were unable to be contacted or identified.

Decision-making in an opt out system where a donation may distress the donor’s family (Q5)

16. Most organisational respondents (72%) thought that if a deemed authorisation donation was likely to distress the potential donor’s family, then the donation should not proceed. There were divided views on this question among charities and voluntary sector groups.

17. A small majority of individual respondents (57%) were in favour of the donation proceeding in this situation. However, the level of support for proceeding in a deemed authorisation situation was not as great as it was for the situation described above, where the donor had explicitly opted in to the ODR. (See discussion of Question 3 above).

18. While some respondents were strongly against families being able to overrule decisions (deemed or otherwise), others prioritised the wishes of the family. Among this latter group, the risk of causing distress, and concerns about possible perceived pressure on families to agree were seen as key reasons for not supporting an opt out system.
Requirement for explicit authorisation in a soft opt out system (Q6 – Q9)

19. The consultation paper explained that in a soft opt out system, where deemed authorisation would generally apply, there could also be 'excepted' categories of people – for whom explicit authorisation would continue to be required. Three excepted categories were proposed: (i) adults with incapacity; (ii) children under a certain age; and (iii) anyone who had been resident in Scotland for less than 12 months.

20. Most respondents (73% of organisations and 79% of individuals) agreed with the three excepted categories. Only faith groups among the organisational respondents were more likely to say that the three categories would not be sufficient in a soft opt out system. Respondents who thought the categories were not sufficient were generally opposed in principle to a soft opt out system. However, some respondents highlighted concerns in relation to one or more of the proposed excepted categories (most often, in relation to people resident in Scotland for less than 12 months), or they suggested a small number of other groups for whom explicit authorisation should be required.

21. Separate questions were included in the consultation to explore: (i) the circumstances in which an adult should be viewed as not having the capacity to make their own decisions about donation; (ii) the age at which deemed authorisation provisions would apply for children; and (iii) whether local authorities should be able to authorise donation following the death of a child in care, if no parent is available.

- **Adults with incapacity**: Respondents thought that the Adults with Incapacity (Scotland) Act 2000 should provide the basis for guidance regarding capacity. However, some wanted clarification about the timeframe for this provision, and how it might take account of cases where a person’s capacity changed over time.

- **Age threshold for deemed authorisation provisions in children**: The largest proportion of both organisational and individual respondents thought that explicit authorisation should be required for all children under 16, and that deemed authorisation should apply for young people aged 16 and over. Around half of organisations (52%) and two-fifths (42%) of individuals expressed this view. However, comments indicated that respondents may have interpreted the question in different ways and therefore these findings should be treated with caution.

- **Children in care**: The largest proportion of both organisational and individual respondents thought that local authorities should be able to authorise donations where a child dies while in care, if no parent is available (46% of organisations and 57% of individuals said this). However, organisations were more likely to say ‘no’ or ‘don’t know’ in response to this question.

Donations of less common types of organs or tissue (Q10)

22. Just under half of organisations (46%) were in favour of deemed authorisation provisions applying to all – and not just the most common – organs and tissue. By contrast, 83% of individuals were in favour of this.

Pre-death tests and treatment for potential donors (Q11 – Q13)

23. Most respondents agreed that clinicians should be able to carry out a range of medical tests on a potential donor before life-sustaining treatment was withdrawn.

24. Among those who disagreed, just over half thought that the tests could be permitted if the person had previously made it clear that they wished to be a donor. A fifth thought the
tests could be permitted if the family provided consent. Just under a third thought such tests
should never be permitted.

25. In addition, a majority of respondents (67% of organisations and 72% of individuals)
agreed that, where a patient's condition is unsurvivable and it will not cause them discomfort,
it should be permitted to administer medication to the patient before their death to improve
the chances of a successful transplantation. Respondents who opposed this proposal
expressed concerns about carrying out treatment on one person for the benefit of another.

Involvement of authorised representatives (Q14)

26. There were different views among organisations and individuals about whether people
should have the option to appoint one or more authorised representatives to make decisions
for them about donation before they die. A small majority of organisations (52%) said that this
was not necessary, while a small majority of individuals (53%) said that this type of proxy
authorisation should be allowed.

27. While some respondents thought that proxy authorisation could be useful in certain
circumstances, others argued that individuals could simply make their wishes known by
opting in or out of the ODR.

Health service initiatives to increase the number donors (Q16 and Q17)

28. A large majority of respondents (81% of organisations and 88% of individuals) thought
that the Chief Medical Officer (CMO) should issue guidance to clinicians to refer almost all
dying or recently deceased patients for consideration as potential organ or tissue donors.
Respondents thought that CMO guidance would support good practice in involving specialist
staff, and help raise awareness across the healthcare workforce. However, there were also
concerns about the need to focus on appropriate cases and maintain the current ethos of the
organ donation system, and the need to consider resource implications.

29. There was also strong support for the proposal to require specialist staff to be involved
in discussions with families about organ donation (81% of organisations and 78% of
individuals were in favour). Respondents thought that involving specialist staff in such
discussions would increase the chances of authorisation being granted, and would have a
positive impact on the wellbeing of families. However, potential resource implications were
also noted, and there was also a view that the absence of specialist staff should not prevent
discussions with families about organ donation. Those who did not support the proposal did
not see it as necessary or were concerned about the resource implications, or about ethics.

Equalities impacts and implications (Q18)

30. Just over half of organisations (55%) and around a fifth of individuals (18%) said they
could identify impacts or implications for particular equalities groups. Respondents identified
possible negative impacts for: those opposed to organ donation including those opposed for
religious or cultural reasons; and various vulnerable, hard-to-reach and socially
disadvantaged groups. Respondents identified positive impacts for black and ethnic minority
groups, and for people with disabilities and long term health conditions, both of whom it was
suggested would benefit from an increased supply of suitable organs for transplantation.

Other comments (Q15)

31. Respondents highlighted a range of issues to be considered if a soft opt out system
were introduced. They also highlighted the importance of continuing with initiatives to
increase successful organ and tissue donations regardless of the system in place.