

NHSBT Board Meeting
January 2019

Organ Donation Consent Legislation – Progress Report

1. Status – Official

2. Executive Summary

Some amendments to the English Bill have been tabled by two Lords from the House of Lords. If these are upheld in the All House Committee, there is a higher risk that the Bill will fall. We continue to provide advice and briefing where appropriate to the Department for Health and Social Care to support the Bill progressing. If enacted, the English legislation will be implemented in April 2020. In addition, Jersey may implement their legislation in Summer 2019 and Scotland in Summer 2020.

Work is underway to implement some of the English commitments arising from the legislation. The new faith declaration on the Organ Donor Register was launched in December 2018 and work on integration with the NHS App continues, along with the development of Communications campaigns to raise awareness of the new legislation. We are also developing project plans to support the operational implementation.

Some funding has already been confirmed / released regarding changes to the Organ Donor Register and Communications plans. We are awaiting confirmation regarding the final funding allocations. However, the timescales for implementation mean that we need to proceed at risk with some work and use ODT baseline funding until we receive this confirmation.

3. Action Requested

- **Note the challenges arising from the implementation timescales.**
- **Agree that operational implementation should proceed at risk using £218k baseline funding, until the Government funding is confirmed.**
- **Note the progress made in developing a campaign to inform the public of the law change.**

4. Purpose of the paper

This paper outlines the current state of the Bills and progress made to date regarding Communications planning and digital transformation. It also summarises the work that needs to be commenced now, in order to be prepared for implementation of the new legislation when it comes in to

force, highlighting the risks and proposing that we proceed with some work, particularly around recruitment, to ensure that the service is ready to meet anticipated increase in activity and that we comply with the new legislation.

An update on progress in developing the public information campaign requested by DHSC is contained in the accompanying presentation from the Interim Director of Marketing and Communication.

5. Background

5.1 England

The Bill has been through Committee report and third reading in the House of Commons. Following the debate in the House of Lords on the 23rd November, some amendments were tabled by Lord McColl and Lord Morrow. These will need to be discussed at the All House Committee and if upheld, the Bill and these amendments will be discussed again in the House of Commons. Given the parliamentary restraints / issues, this would mean that there is a higher risk of the Bill falling. If the amendments are dropped, it is likely that the Bill will be Enacted in March 2019 and implemented in April 2020.

5.2 Scotland

The Committee stage completed in November and the report is expected in January 2019. Subject to further parliamentary processes, it is anticipated that the Bill will be enacted in the Summer 2019 and implemented in Summer 2020.

5.3 Crown Dependencies

Jersey has introduced legislation, which is anticipated to be implemented in Summer 2019. The Isle of Man is progressing deemed consent legislation and may also wish to implement in 2019. Guernsey is unlikely to introduce legislation before 2020.

6. Operational Implementation

6.1 We need to undertake some activity now, if we are to be ready for the change in legislation from April 2020. This work will need to proceed at risk until the outcome of the Bills are clearer and additional Government funding is confirmed.

6.2 The costs would therefore need to be absorbed through baseline activity and safeguards / milestones put in place to stop activity if necessary. These are detailed in Appendix A, but in summary:

- i. Internally appoint 2 project leads to support implementation in Organ Donation & Nursing and Education and Governance.
- ii. Appoint 2 Project Managers and a PMO Co-ordinator to support the development and delivery of detailed project plans and associated programme governance.
- iii. Commence the recruitment process for 27 additional Specialist Nurses for Organ Donation (SNODs). The lead time for getting SNODs recruited and

fully trained is 12 months. This will require funding 3-6 months of recruitment support from the workforce team.

- iv. Commence recruitment for additional 6 professional development staff and 1 complaints team staff member within the ODT Governance team, to support increased activity associated with the legislation.
- v. Commence recruitment for 1 additional team member in the Clinical Directorate Statistics and Audit team to support additional activity.
- vi. Authorise the National Call Centre to recruit staff to support the anticipated increase in activity.

7. Funding

- 7.1 We are awaiting confirmation from DHSC regarding the final funding allocations. The detailed costings were provided in the November Board papers. A summary of all the costs are provided in Table 1 below.

Table 1

| | Cost Per Year | | | | | |
|--------------------------|---------------|----------|---------|----------|---------|-----------|
| | 2018/19 | 2019/20 | 2020/21 | 2021/22 | 2022/23 | Recurrent |
| ODR | £689k | £1.888m | £470k | £441k | - | - |
| NORS | £0 | £4.453m | £5.24m | £6.18m | £7.72m | £9.22m |
| Operational | £90k | £1.336m | £2.21m | £1.893m | £1.913m | £1.913m |
| Comms | £200k | £9.5m | £6.3m | £3m | - | - |
| Faith declaration | £79.8k | - | - | - | - | - |
| NHS App | Up to £950k | - | - | - | - | - |
| Totals | £2.009m | £17.177m | £14.22m | £11.514m | £9.633m | £11.133m |

- 7.2 Scotland have confirmed the funding for additional SNODs to manage the increase in their donors. The following funding has already been confirmed by DHSC (these figures are incorporated in to the amounts in Table 1):

- Communications planning - £200k for FY2018/19
- Faith Declaration – £80k

- 7.3 The costs in Table 2 will be incurred from baseline allocations in the current year if the Board agrees to proceed at risk. These costs are up to the end of the March 2019, by which point it is anticipated that the DHSC will have confirmed funding allocations. Should this not be the case, costs will continue to be incurred at risk until a final decision is made regarding funding allocations and future resources for the programme. In addition to the figures in Table 1, we are in the process of reviewing the level of project support and roles required to implement the change in legislation. The funding for the National Call Centre (NCC) costs have reduced from the original amount of £247k to £208k.

Table 2

| Activity | Amount | New funding request |
|---|--------|---------------------|
| Accountable Executive and their backfill | £18.4k | No |
| Project Leads and their backfill for 3 months initially until DHSC funding is confirmed | £52k | Yes |

| | | |
|------------------------------|----------------|-----|
| 2 x Project manager and PMO, | £39k | Yes |
| SNOD recruitment | £0 | No |
| Governance recruitment | £0 | No |
| Communications recruitment | £0 | Yes |
| NCC recruitment | £208k | Yes |
| Statistics team | £8.5k | Yes |
| Totals | £325.9k | |

8 Communications

8.1 The Government has committed to a 12-month public information campaign in advance of the new legislation being implemented. DHSC has defined what this should consist of to achieve the 80% awareness target that is desired and received legal advice that it is unlikely to be legally challenged for not taking reasonable steps to properly inform the public.

8.2 NHSBT planning for the campaign is now well advanced to ensure we are in a position to launch activity from April 2019. NHSBT already have the third-party contracts in place to deliver what has been requested in the communication implementation plan for 2019 and progressing recruitment of additional resource but will not appoint until funding is confirmed.

8.3 Awareness of the change in law is currently at 54% of the population¹. NHSBT have made it clear that raising awareness to 80% is challenging based on comparative spend levels with Wales and that DHSC will need to secure support from across government, the NHS and charity partners to extend the non-paid frequency of the campaign. NHSBT has been clear with DHSC that its role is to deliver the campaign set out and that we cannot be accountable for it delivering the 80% target awareness over the 3-year period.

8.4 A campaign advisory group has been established to help ensure that the campaign is informed by best practice and enjoys a broad coalition of support from partners. The group includes representatives from government departments, NHS bodies, academia, faith groups and charity partners. The insights and feedback from this group are helping to shape our campaign approach.

8.5 The accompanying presentation from the Interim Director of Marketing and Communication summarises the research and campaign development activity to date. We have now worked with our creative agency to develop three potential creative routes which are currently being tested in focus groups. We will be presenting the outcome of this research to the Minister at the end of February.

9 Digital

9.1 The new faith declaration within the Organ Donor Register was launched on the 12th December 2018. In the first 74,591 opt-in registrations received since the launch:

¹ Wave 1 of the research was carried out online by Kantar among a representative sample of 2,129 respondents in England, during October 2018.

15,565 (21%) ticked 'yes: this is applicable to me'; 52,910 (71%) ticked 'no: this is not applicable to me'; 6,116 either ticked 'prefer not to say' or chose not to respond to the non-mandatory question.

9.2 Work to integrate the ODR with the new NHS App is progressing on target. The solution design and requirement specifications were completed on time in December 2018. The development work on the ODR system is advancing well and initial versions of the ODR Application Programming Interfaces (APIs) required have been installed for initial testing. Development of the NHS Application and integration layer has commenced. A further iteration of the NHS App 'prototype' is being reviewed in readiness for user testing on 17 January 2019. Planning of testing and service transition activities is in progress. The preparation of the systems infrastructure is progressing to plan. While the project remains on track for an end of April release it is recognised the timelines do not allow for any contingency and so the overall project status remains at 'amber'.

10 Risks and Issues

- 10.1 There are the following new risks and issues, in addition to those highlighted in previous Board papers:
- 10.2 Given the amendments tabled in the House of lords, there is a much stronger risk of the English Bill falling. This risk will be clearer after the House of Lords Committee meeting.
- 10.3 It is possible to delay any further work in England regarding project planning, business cases, recruitment etc, until it is clearer if the English Bill will be enacted. However, this will mean that we will be unlikely to be ready to meet the implementation deadline of April 2020 if the Bill is successful and therefore risk being non-compliant with the change in legislation in England.

11 Conclusion

Detailed planning for the implementation of the legislation is currently progressing at risk whilst the outcome of the English legislation is unclear and the funding from DHSC is not confirmed. This work carries resource and funding implications for NHSBT. The work could be paused but this in turn will risk NHSBT not being able to deliver an effective service and not being legally compliant should the English Bill be successful.

NED Scrutiny

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Appendix A - Proposal: Proceeding at Risk with Implementation for Deemed Consent Legislation

Note – the costs outlined below are up to the end of the March 2019, by which point it is anticipated that the DHSC will have confirmed funding allocations. Should this not be the case, costs will continue to be incurred at risk until a final decision is made regarding funding allocations and resources for the programme.

| Activity | Detail/ Rationale | Cost | Risk Mitigation |
|---|--|-------------|--|
| Formally appoint an Accountable Executive for the Opt Out Programme and their associated back-fill. | To ensure appropriate Governance is in place, the programme needs to be overseen by an Accountable Executive. This person will be recruited internally and will need to have their post back-filled. | £18.4k | The successful candidates will be informed that the role will be on a secondment basis and subject to change dependent on the outcome of the legislation process. They will be able to be quickly moved back to their substantive posts. |
| Appoint 2.5wte project leads – one for Nursing and one for Governance and their associated back-fills; 0.5 wte for Quality. | Each of the different workstreams within the opt-out implementation programme needs a lead to develop a project plan and advise on the internal business case development. There is also other work commencing, such as the development of Human Tissue Authority Codes of Practice, which needs resourcing to ensure that NHSBT is effectively represented. It is anticipated that these will be internal candidates, whose current posts will then need backfilling. It will take some weeks to recruit. | £52k | The successful candidates for both the project leads and any required back-fills will be informed that the roles are a secondment only to the end of the financial year and may be subject to renewal, dependant on the outcome of the legislation and confirmation of Government funding. |
| Commence recruitment of 2 x Project Manager and a PMO Coordinator to support | As a formal programme of work PMO support is required to set up the programme, support business case/initiation and documentation, planning, reporting and Governance. | £39k | It will take a couple of months to undertake recruitment of these roles. The process can be stopped at any time in response to an unexpected change in the Legislation in England and we |

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| Programme Delivery. | | | would not award contract until the funding confirmation has been provided by DHSC. |
| Commence recruitment process for Specialist Nurses for Organ Donation (with workforce support). | We anticipate needing 27 additional SNODs in place by April 2020 to support the anticipated increase in donors. It takes 6 months to complete the recruitment process for a new cohort of SNODs and a further 6 months to train them. This process therefore needs to be started now, if we are to have the necessary SNODs in place within the timescales agreed. The Nursing project lead will work with HR and Governance teams to recruit and train the teams. | £0 | It will take some months to undertake the necessary work before actual interviews/ recruitment can commence. This process can be stopped at any time in response to a change in the legislation in England and we would not actually recruit until the funding confirmation has been provided by DHSC. |
| Commence recruitment process for 6 additional professional development staff within the ODT Education team | The Education team will need to be increased to support the additional training for organ donation teams arising from the legislation. We need to commence this recruitment process now if we are to have the teams in place and trained in time for the anticipated increase in activity. | £0 | As above – no actual recruitment will occur until confirmation of funding is confirmed. |
| Commence recruitment for 1 additional complaints team member within the ODT Governance team. | Based on experience with implementing the legislation in Wales we anticipate 8-fold magnitude of around 450 complaints arising from the new legislation. This workload is already increasing as the Bill is progressing and we anticipate needing a new member of staff in April 2019. | £0 | As above – no actual recruitment will occur until confirmation of funding is confirmed. |
| Recruit additional statistician | Additional Band 5 statistician to manage increased activity in the statistics team required to support changes to legislation | £8.5k | Inform the successful candidate that this will be a fixed term contract for 6 months, but with a |

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| | <p>and subsequent monitoring. It will be difficult to recruit to this post without a fixed term contract of at least 6 months. It is anticipated that the DHSC will want additional monitoring of the impact of the new faith declaration on the ODR and integration with the NHS App, so this additional work is not entirely dependent on the success of the legislation.</p> | | <p>possible option to renew subject to the progress of the legislation.</p> |
| <p>NHS Organ Donor Line</p> | <p>An Opt-Out Organ Donation Support Line is to be established to offer support to members of the public regarding the new legislation. The existing provider of the NHS Blood and Organ Donor lines will provide the additional service which must be ready to go-live prior to an announcement that the legislation has been passed (potentially April).</p> <p>The provider requires 13 week lead times to recruit and train additional contact centre staff.</p> <p>Additionally advanced work is required to establish the required telephony systems & infrastructure.</p> | <p>£208k</p> | <p>The NCC can release staff with a 6-week notice, should the Bill fall.</p> |