Healthcare Improvement Scotland

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Commissioning Transplantation to 2020

Gathering views from people about transplant services

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Contents

1 Background

1.1 In 2013, NHS Blood and Transplant, on behalf of the four UK nations, and the Scottish Government published two complementary strategies which aimed to increase transplantation levels in the UK over 7 years. The aspiration is for the UK to become one of the best performing countries in the world for organ donation and transplantation.

1.2 Taking this forward, NHS National Services Scotland, National Services Division, which commissions solid organ (e.g. heart, kidney, liver) transplant services for people in Scotland, undertook a planning exercise, called ‘Commissioning Transplantation to 2020’. It involved transplant recipients, transplant services, NHS Blood and Transplant and the Scottish Government. The aim of the exercise was to increase the quality of services and the number of transplants provided as well as to improve transplant success rates.

1.3 An initial assessment undertaken by National Services Division suggested that implementation of the strategies is likely to increase solid organ transplantation levels in Scotland by 48% (from 344 in 2012-13 to around 510 in 2019-20). Capacity issues brought about by increased transplantation were also considered. It is anticipated that increased transplantation levels will bring the benefit of reducing pressures in other associated areas of treatment including dialysis, insulin therapy, hospital admissions, medical management (which include some high cost drugs) and surgery.

1.4 The Scottish Health Council was asked by National Services Division to gather views from patients who had received a transplant, focusing particularly on the transplantation process, aftercare experience and the impact of receiving a transplant on the patient, family and carers.

1.5 This report describes the approach taken by the Scottish Health Council’s local offices and summarises the feedback received from people who took part as well as highlighting some of the recommendations arising from the themes supported by the group discussions.

2 Approach

2.1 In the first instance, National Services Division conducted a survey (through an online questionnaire) of solid organ transplant recipients to capture information about the quality of the current service. It also aimed to identify areas for improvement and get a better understanding of how a transplant had impacted on the lifestyles of recipients.

2.2 A total of 134 completed questionnaires were received with 91% of respondents indicating that they were satisfied or very satisfied with the transplant services. A number of key themes emerged from the survey responses, which National Services Division wanted to explore further with patients. These related to referral processes, patient assessment, waiting lists for transplant, transplant surgery and inpatient stay, patient care post transplant and impact of the transplant on the recipient.

2.3 Survey participants were asked whether they would like to take part in a more in-depth group discussion about their transplant experience. The aim was to explore in more detail the themes which emerged from the online survey. Twenty two people volunteered to take part.

2.4 In response to a request from National Services Division to gather those views, the Scottish Health Council's local offices organised and facilitated five discussion groups close to where the majority of patients lived, namely Edinburgh, Glasgow (2), Kilmarnock and Kirkcaldy. Two interviews were also conducted (face to face and telephone) with people who were unable to attend a discussion group but had expressed an interest in sharing their experience. All 22 people who volunteered took part.

2.5 Each discussion group followed a similar format although the time allocated for each session varied depending on the needs of the group. The questions posed to participants were grouped together with additional prompts so that views were captured on:

- the experience of the transplant pathway and care provided
- the quality of information given to patients during the transplant process
- the level and quality of emotional, psychological and social support available during the transplant process
- the quality of healthcare after transplant and post discharge from hospital, and
- the impact on the lifestyles of transplant recipients, their family and carers.

With the exception of one group, each session had a representative from National Services Division in attendance to discuss any specific questions participants had.

2.6 In addition to organising and facilitating the discussion groups, Scottish Health Council staff recorded the feedback, produced a report of each session, conducted an evaluation of the sessions and completed an equalities monitoring exercise. We will use the feedback gathered through the participant evaluation to refine our approach to gathering patient views in future.

3 Feedback

This section summarises the feedback received from people who took part in the discussion groups. A separate report, produced by National Services Division, which combines the results of the online survey with the feedback from the Scottish Health Council's discussion groups, as well as the other findings of the forward planning group, is available at www.nsd.scot.nhs.uk/publications/servicereviews.html

Referral process

3.1 The questionnaire feedback indicated that the majority of respondents felt that the process was generally straightforward and efficient. 85% of respondents felt that they were referred at the right time, but 10% felt that they should have been referred earlier and 5% were unsure.

3.2 The focus group participants talked about the timeliness of information provided and some commented that they had not been told that they were referred for a transplant assessment and talked about delays in the referral process. Some said that a lack of information during the referral process was particularly concerning.

3.3 While a number of people felt that they were fully informed at this stage in the process, others indicated that more information would have been helpful. However in one instance paperwork was misfiled and another person indicated that their blood samples were misplaced between transplant unit and local hospital.

Assessment

Information provided

3.4 The questionnaire feedback indicated that the majority of people who responded to the questionnaire (93%) were satisfied with the care provided by the transplant team during their assessment for transplant. In the main, this was supported in the focus group discussions where people said that all the information was provided, however one participant commented that "it was good to have a partner there as although you take it in at the time and you think you understand, by the time you leave the consultants room you forget a lot of the discussion."

3.5 A number of participants felt that they were given adequate information during the assessment process through booklets and other materials and via discussions with consultants. Several felt that there was no element of decision making involved about treatment but this was mainly because a transplant had become the only option. They still felt involved, however, in conversations about their care.

3.6 Several participants expressed dissatisfaction regarding information provided in advance of the assessment. One participant described the process as “terrifying – lack of understanding over this i.e. not an exam with pass or fail.”

3.7 Participants felt though that there was a lack of information about how decisions were made particularly about whether or not to put a patient on the waiting list for transplant. The process was described as unclear and sometimes seen as “unfair”. One participant said: “Nobody lets you know that you sometimes have to challenge decisions and actually fight your case”.

Psychological impact

3.8 Some participants said they were offered the opportunity to talk over any worries and concerns with a transplant co-ordinator or consultant although some felt that more support was needed and would have been helpful when first told about the need for a transplant. Similarly, participants also said that the “assessment week” could be very confusing and overwhelming and some described it as a “devastating experience” for anyone who was not accepted on to the transplant waiting list.

3.9 Some participants said that the assessment process felt emotionally draining, not only for the patient, but for their family and carers. One participant said: “Partners and family tend to be left in the lurch after the diagnosis”.

Waiting list

Information received

3.10 89% of the questionnaire respondents felt that they received sufficient support for their healthcare needs whilst on the transplant waiting list. 23% of respondents felt that they did not have sufficient support for their emotional needs and it was noted that a quarter of respondents indicated that their relatives did not have sufficient support for their emotional needs during this period.

3.11 The focus group discussion mirrored this response. While they had felt that they had received sufficient support they identified areas for improvement. In relation to feedback about waiting for transplant, participants felt there was a need for more information about where they were placed on the list (or even that they were still on the list) and how it worked in practice. One participant said that they had waited nine years for a transplant and at times, especially after commencing kidney dialysis, they were not always sure whether or not they were still on the list for transplant.

3.12 Some participants referred to the frustration and stress caused by what they described as “false alarm calls” i.e. those that did not result in transplant. They felt strongly that more information should be given about the potential for “false alarms” when a patient is called about an organ becoming available but the operation is then delayed or cancelled. Whilst participants acknowledged that cancellation was sometimes inevitable, they said that prior warning or advance notice that it was a possibility would have helped.

3.13 Some suggested the need for one-to-one support rather than the group sessions that took place; others felt they were being left alone to find the information they needed. There was also a view that there needed to be more information available to patients about the importance of taking medication.

Psychological impact

3.14 Participants expressed strong feelings of “abandonment” whilst being on the waiting list. One said: “You are put on a list and forgotten about”. People also felt that the time spent on the waiting list was “incredibly stressful” especially when quite often they were dealing with multiple other issues such as a decline in their physical health, thinking about where the organ needed to come from, and the potential of a long wait for treatment.

3.15 Other participants mentioned how sensitive and difficult it was to ask family members to donate an organ (e.g. kidney); there was a suggestion that a patient support group would prove helpful. One participant said: “When I got the call saying there was an organ available, it was a shock – I didn’t think it was real”.

3.16 One participant described being an inpatient in their local hospital whilst waiting for an organ to become available. They described how one night they heard the telephone ringing at the nurse’s station but no one came to answer it for some time. It transpired that it was a call about an organ becoming available. This participant wondered what would have happened if no one had ever picked up the telephone and so recommended that there should be greater emphasis or different arrangements when people were waiting for calls about availability of organs. One participant shared an experience of being asked to detour to another hospital to pick up their medical notes prior to heading to the hospital for transplant surgery.

Transplant surgery and inpatient stay

Information

3.17 Overall, participants praised staff that cared for them in the transplant units across Scotland and the United Kingdom. They said they particularly appreciated the expert knowledge staff clearly had about transplantation as well as their caring approach. Participants felt, however, that the transplant units were "understaffed" at times. There was mixed reaction to participants' experience of transplant co-ordinators – some finding them helpful, others not. One participant advised that the most reassuring information often came from conversations with others who had been through the transplant process.

3.18 Whilst one participant said they had received information about transplant surgery through booklets which also described what to expect after surgery, others felt "unprepared for the next stage of life" post surgery and particularly when it came to what to expect regarding the side effects of drugs. Participants felt that clinicians could sometimes be so focused on the medical issues of transplantation that they "neglected" to fully inform patients about other important issues (e.g. unrealistic expectations given for returning to work).

Psychological impact

3.19 From the discussions, it emerged that not all patients were routinely offered psychological support within adult services (it was acknowledged as being available within children's services). There were some views that clinicians sometimes "lacked sensitivity or people skills" and there was a much greater need, or more emphasis needed to be placed, on support for family members.

3.20 A recurring theme was around the psychological effect of the whole transplant process on a patient's family and carers. A number of participants mentioned that their family was not given any support throughout the process. Examples were relatives being left unattended during surgery with no updates provided or without being offered a place to go. One participant was particularly complimentary about the psychological support provided by the Golden Jubilee National Hospital and recommended that practices there could be replicated elsewhere.

3.21 Other concerns raised by participants in relation to inpatient stays were about the lack of bed availability in some hospitals, concerns about the potential of infection in multiple bedded wards, and the availability of food (not always what was ordered).

Care after transplant (aftercare)

Information available

3.22 The questionnaire asked respondents to provide feedback on their experience of aftercare.

- 57% were satisfied or very satisfied with their GP service during the first six months after transplant
- 66% were satisfied or very satisfied with the care provided by their local specialist, and
- 85% were satisfied or very satisfied with the care provided by the transplant unit during the first six months after transplant.

3.23 The focus group participants mentioned that good support was available by being able to ask questions after treatment either by email or telephone. Some participants said it was unclear who they should contact if they needed assistance or had a specific problem after being discharged from hospital post surgery (i.e. NHS24, transplant ward, GP or local hospital). More specifically, some participants said that it would be helpful if there was a system whereby they could access blood (and other) results online.

Psychological impact

3.24 Overall, participants felt that the level of psychological and emotional support available after transplant surgery varied widely. Some described receiving support at their local hospital or through social work services; some had found support via social media and others felt that none was available to them at all. Where there was no (or limited) support, participants said this made them feel “abandoned” after discharge.

3.25 Other participants referred to the effect that medication had on their emotions after transplant surgery; others referred to the effects on partners who “suffered emotionally” after surgery. One participant suggested that a “patient orientation group” could be hugely beneficial in getting an understanding of what patients can expect post transplantation.

3.26 When asked “What was good healthcare after transplant?” participants described:

- preventative and anticipatory care
- care which was responsive to individual physical and emotional needs
- having clear expectations about health in the short, medium and long term
- timely, adequate and effective information sharing between the transplant unit, local hospital and GP

- development of local support and local care co-ordination starting on discharge
- local services empowered to undertake non-specialist tests
- interested and proactive GPs and dispensers
- straightforward and timely access to the correct (branded) medications, and
- access (and fast track where necessary) to skin and skeletal checks, blood tests, physiotherapy, dietician, and psychology services.

3.27 Participants acknowledged that patients needed to take ownership for their own healthcare although they felt that there was a need for support for patients to take such an approach. Many participants described how they had encountered difficulties in dealing with their GP on issues associated with transplantation and a general concern about the GP's knowledge and/or interest in organ transplant issues. That said, a few participants mentioned that their GP was able to offer them emotional and psychological support.

3.28 One big concern which emerged was the way some patients felt "abandoned" due to lack of support after discharge. In one instance a comparison was made that, after the birth of a baby, a midwife would visit for check-ups, however, after transplant there was no advice or check-up. Concerns also emerged about follow-up procedures, such as skin and skeletal checks, which participants said tended not to happen.

3.29 There were major concerns expressed about access to medications after transplant. A number of participants indicated that they kept a stockpile of medications because they often experienced delays in getting their prescriptions. They also mentioned difficulties with the supply of medication – in the main attributed to pharmacies not being able to obtain the prescribed medication. Furthermore, there were concerns raised about the inadvertent switching of a number of branded immunosuppressants (medicines that lower the body's ability to reject a transplanted organ) to generic medicines. As critical-dose drugs with a narrow therapeutic index, these immunosuppressants have an associated risk of toxicity and graft rejection if patients are switched between brands without careful medical supervision. Patients felt, therefore, that there needed to be increased awareness about the importance of remaining brand consistent.

Impact on the transplant recipient's life

3.30 The feedback from questionnaires notes that participants stated the positive effect that receiving a transplant had on their family including the opportunities to get married, have children, or simply to "lead a normal life". They said that receiving a transplant provides opportunities that were sometimes unavailable (or more difficult) beforehand. They mentioned greater freedom now that they were no longer on dialysis. Others were able to return to work or start a career, able to pursue education, and some became involved in sports and exercise. Some felt stronger emotionally. On the other hand, some mentioned a negative effect on their mental health; for example they were coping with anxiety and depression, while others were dealing with side effects from medications.

3.31 The focus group discussion raised mainly positive feedback. Common themes relating to the impact of receiving a transplant on the lives of participants were described as:

- being alive and getting a quality life back
- being in better health than before the transplant
- being physically active and taking part in sport (a number of people indicated that they had gone on to take part in the Transplant Games)
- returning to work, start in new employment and/or pursue further education (although some participants had encountered difficulties in returning to employment due to the time spent off sick and/or perceptions of perspective employers about the ability of transplant recipients to fully contribute within the workplace)
- changes in interpersonal relationships and the need to stay well
- side effects caused by transplantation (such as fertility issues)
- psychological effects and feeling more emotional than previously
- no longer being viewed as a “sick person” (this was viewed both from both positive and negative perspectives with some participants indicating that those around them expected them to be automatically “cured”)
- issues with accessing insurance for holidays, and
- issues associated with accessing state benefits (such as Disability Living Allowance).

4 Next steps and recommendations

4.1 A full report “Commissioning Transplantation to 2020 - Transplant Recipient Feedback” was published by National Services Division and circulated to all participants. Reports about specific transplant centres have also been distributed to staff and management in all the transplant units across Scotland.

4.2 Based on the feedback received from participants, National Services Division has recommended a number of proposals aimed at improving the patient experience. In total twenty five recommendations were made, twelve of which are directly linked to the themes arising from the focus group discussions.

These are as follows:

4.2.1 All of the nationally commissioned transplantation services should work with living donors, patients and the voluntary sector to seek feedback to:

- continually improve the quality of services for their patients
- develop patient reported outcome measures (PROMs).

4.2.2 The transplant services should work to develop patient information to reduce anxiety and better support patients. Additionally, better signposting to voluntary sector organisations and patient associations/peer support groups will support individuals who need or have received a transplant.

4.2.3 The transplantation services should work to ensure that all patients are offered appropriate psychological support throughout their experience of the transplant service. Patients and living donors who require psychiatric input should also have access to a psychiatric assessment.

4.2.4 It is essential that the transplant services continue to promote their services to referrers and remind referrers of the appropriate thresholds for referral.

4.2.5 The transplant services should offer all transplant patients the opportunity to jointly create care plans which can be developed by local services. These care plans should support the development of local aftercare (e.g. psychology, diabetes control) and local tests (e.g. skin surveillance, skeletal checks).

4.2.6 It is recommended that where possible and viable, patients are followed-up locally through outreach clinics in order to reduce the need to travel for patients. The services should liaise with NHS 24 Scottish Centre for Telehealth to explore options for the usage of telemedicine.

4.2.7 It is recommended that PatientView (an online tool that shows test results, and information about diagnosis and treatment) be expanded to all transplant patients, as the impact on patient empowerment and independence would be significant.

4.2.8 In producing discharge information for patients, SIGN Guideline 128 (www.sign.ac.uk\\guidelines\\fulltext\\128\\index.html) should be followed and Immediate Discharge Documents and Discharge Summaries should ideally be sent out to GPs/referrers on the day of discharge and within a week of the patient's discharge date, respectively. Additionally, outpatient clinic letters and admin letters should be dispatched within two weeks of the clinic date.

4.2.9 A range of local initiatives have been recommended by the Reference Group to try to mitigate the risk of inadvertent branded prescribing, including the following.

- The inclusion of alerts in Health Board bulletins.
- Ensuring patients understand the importance of staying on a consistent brand, for example through use of patient-alert cards.
- Targeted guidance to prescribers and pharmacists in primary care.
- The inclusion of on-screen alerts to GPs at the point of prescribing using the 'Scriptswitch' software. There are also in-built warning in the EMIS and Vision systems.
- The inclusion of on-screen alerts to pharmacists at the point of dispensing using the Cegedimrx Nexphase and Pharmacy Manager system, Pharmacys UK and Rx Systems.
- Practice based pharmacists checking GP-held records to ensure branded prescribing.

4.2.10 Analysis of prescribing data to identify where generic prescriptions are still being issued (it is possible to interrogate data down to individual patient/prescriber level).

4.2.11 The Scottish Government has agreed to send out a formal letter to all prescribers and dispensers in Scotland to raise awareness and inform these groups of the risks of the inadvertent switching of medicines from branded to generic products.

4.2.12 The physical benefits of transplantation should be supported by other areas of support offered to patients. Certain strategies, such as improved psychological and social support, have been highlighted as having positive impact on improving the quality of life of transplant recipients.

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The Scottish Health Council conducted an evaluation of the discussion groups and received feedback. The results of the evaluation are available from the Scottish Health Council on request.

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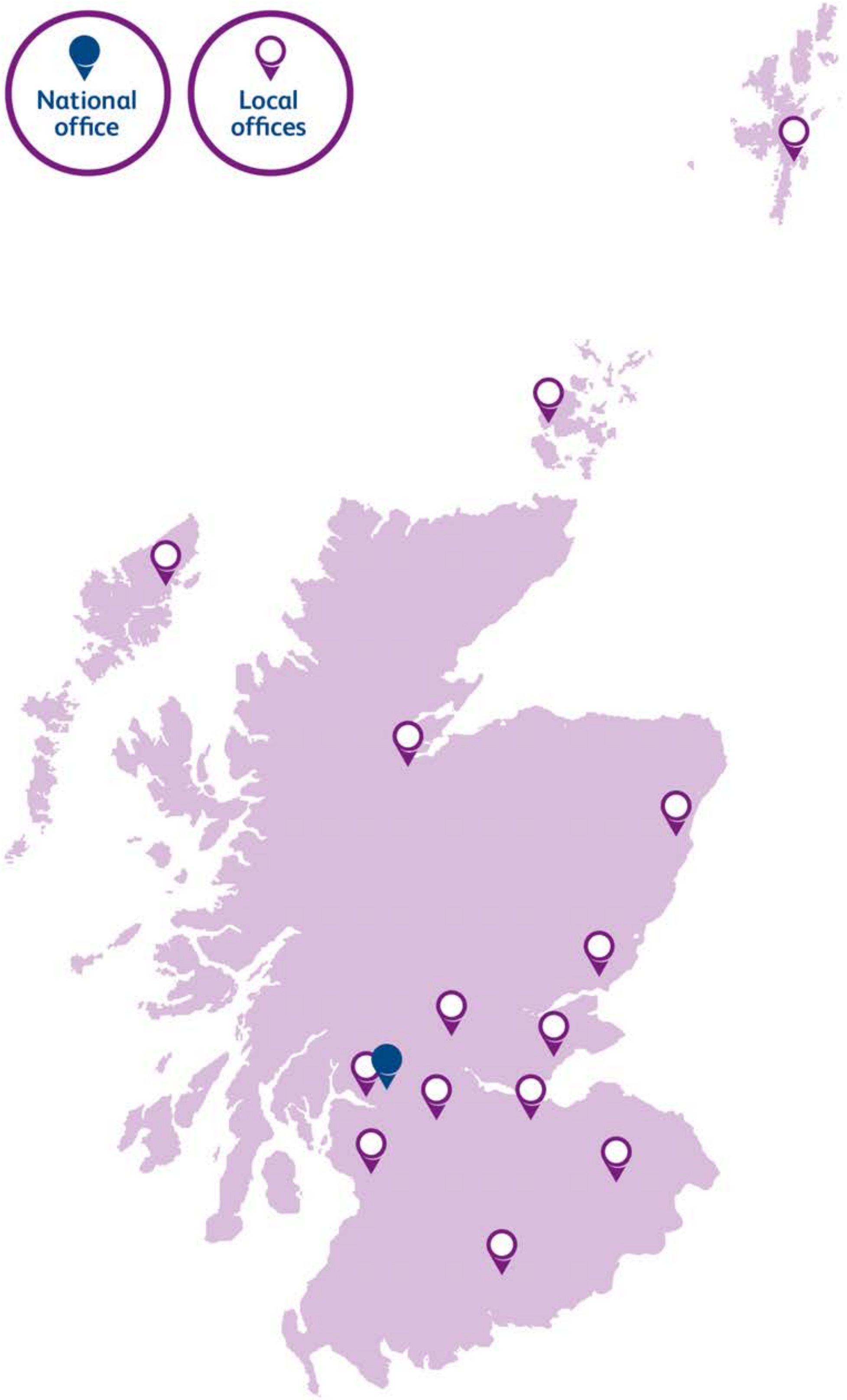

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