



Summary of Organ Utilisation Group Meeting, 5th August 2021

The Chair welcomed members to the second meeting of the Organ Utilisation Group (OUG) and introduced Fiona Loud and Deirdre Kelly, who had been invited as observers on to the OUG in their roles as Co-Chairs of the OUG Stakeholder Forum.

The focus of the meeting was on:

- (i) hearing more from the patient perspective about where improvements can be made in transplantation.
- (ii) advising on the subgroups Terms of Reference, membership, and papers.
- (iii) advising on the stakeholder engagement approach (workshop and call for evidence).

No conflicts of interest were declared.

1. Notes of last meeting and matters arising

The Stakeholder Forum Chairs had been appointed with Fiona Loud as the Patient Representative Co-Chair and Deirdre Kelly as the Clinical Co-Chair. They were in the process of establishing the Forum.

2. The patient perspective

The patient representatives on the group spoke about their experiences with organ transplantation and recommendations for where improvements should be made. A copy of a presentation is at Annex 1. The following key points were made:

- Communication
 - Concern about whether the right information is shared between the various teams who provide care pre- and post-transplant
 - There needs to be easy, effective ways for patients to contact the right services to support them in managing their condition
 - Improved communication and collaboration between teams would support continuity of care through the different stages of the transplant service
 - Patients on the list who are unwell, scared and uninformed are not in a good position to make treatment decisions. Communication should be timely and information provided at point where patients are able to make decisions about their care.
 - Patients post-transplant may be unwilling to raise problems or concerns, as they would feel ungrateful for their transplant
- Patient and carer support
 - Important that good psycho-social support is available for patients pre-and post-transplantation.
 - Need to ensure that, post-transplant, patients do not 'fall through the net' as it is clear who is responsible for their care
- Inequity of access

- It is important to ensure there are no disparities in referral practices across the country which influence the likelihood of being listed for transplant in a timely manner. (e.g. some referring too early, or only when a patient is likely to be listed)
- Delay in corrective procedures influences patient outcomes
- Socio-economic inequity impacts on the likelihood of getting a transplant – patients and their carers may not be able to afford to stay in hotels during the assessment process, which impacts on their likelihood of receiving a transplant.
- Avoid ‘post-code lottery’ for bridging services such as EVLP.

3. Stakeholder engagement: Communications strategy; Online call for evidence; Stakeholder list

Members discussed the approach for the online call for evidence. The following points were agreed:

- Should be issued in advance of the subgroups being established, to form part of the evidence base for consideration.
- Needs to be flexible to enable patients, clinicians, Government, professional groups etc to provide evidence
- There should be a series of tick-box questions at the start, to support analysis. These should include:
 - Organ type
 - Deceased or living transplantation
 - Stage of the care pathway
 - Which of the subgroup topics the evidence addresses (workforce; standards; commissioning; Systems Architecture & Data Handling)
 - Geographical region of the respondent
 - Whether the response was on behalf of an organisation or as an individual (and name of organisation if relevant)
 - Role of the respondent (e.g. surgeon, patient, carer etc)

Members discussed the approach for a stakeholder workshop. The following points were agreed:

- There may be a need for more than one workshop – subgroups may decide to hold workshops and it is possible that a workshop would be needed after the recommendations were drafted.
- The workshops should start with scene-setting about transplantation and the remit of the OUG.
- Workshops should be online
- There should be an international meeting at a later stage, to review draft recommendations.

4. Subgroups

It was agreed that there should be four subgroups:

- Commissioning
- Standards
- Workforce
- Systems Architecture & Data Handling

Members advised on the Terms of Reference and expertise required in each subgroup.

Next steps

Next steps were agreed as:

- Secretariat to liaise with DHSC and Chair to establish subgroups
 - Secretariat to start drafting agenda, invites etc for the stakeholder workshop
 - Secretariat to draft online call for evidence and share with subgroup Chairs and OUG members for comment
 - Secretariat to draft summary of the meeting to share with stakeholders using existing vehicles for communication within NHSBT and BTS.
 - Members to provide any further comments, including recommendations for international meeting
-
- Date of next meeting: 28th September

Annex 1

Patient perspective slides and information



Introduction

- We had 13 patients take part in the focus group
- All participants from diverse backgrounds and all kidney patients
- 3 dialysis patients and 10 transplant patients.
- One forum and one survey





Key Points



KEY POINT 1

Communications

Outpatients/Patient support

Ward

Clinic

KEY POINT 2

Delay in transportation/Travel to Transplant centre.

KEY POINT 3

Support (tick box exercise)

KEY POINT 4

Delay in corrective procedure

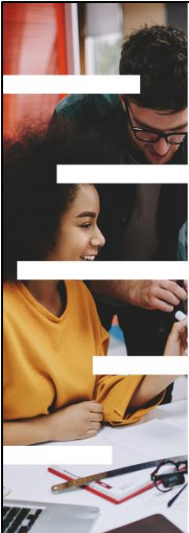
KEY POINT 5

Toast

KEY POINT 6

Contact numbers not working

10



COMMENTS

Comments on improvements were insightful and showed what matters to patients post-transplant. There are a couple of general themes as can be seen in "what is not working". Communication and Support came out top on the list.

COMMUNICATION & SUPPORT

"The care given to Kidney transplant patients, especially after having a transplants needs to improve. Lately, it's about ticking boxes to say we have done our part. Now go home? No questions about your home life, who helps you or what you have access to in the community and can get access to in terms of help. You are told to go to your GP, like your GP knows all your needs after a transplant. Sometimes, you get to the GP, and he has not even received your discharge letter."

"At some stage it would be nice to be asked how do you feel or what do you think? I don't recall my thoughts & feelings being checked on yet despite 4 years of clinic appointments. It may well be that I'm not yet at transplant weight as it's a way of avoiding having to make a decision I don't want to have to make."

"To have more doctors in the clinic to avoid longer waiting times."

"Recruitment of ambassadors or peer mentoring"

"I think the system of getting you back in, whilst I understand the reasons, it made clinic extremely stressful because I was always (still am) that call. I was in every fortnight for 4 months. It took its toll on me, High Peak, Derbyshire is zoned for Manchester, so you have a long journey."

"The satellites units connected to Southmead Hospital have gone through tremendous cost cutting changes, so units are unable to offer the basics such as toast."

What Works Well

- "The system they have now where you get a number & wait is better, I go about once a month & have done since my transplant."
- "They monitor kidney function very well."
- "The routine checks to monitor the level of improvement and the constant reminder on wellbeing."
- "Clinical research/post transplant care/development of new drugs/ethnic minority campaigns"
- "The dedicated pharmacy team have been excellent in both communication and monitoring, working well with me as the patient and with the consultant. I feel confident in my medication-taking because of this."

