



Jas Parmar

Associate Medical Director Patient Engagement

Theme 1:

placing the patient at the heart of the service

Recommendation 1

- Patients who are being considered for transplantation, referral or listing must be supported and have equal access to services irrespective of personal circumstances, including ethnicity, geography, socio-economic status or sex.

Recommendation 2

- Transplant services must be run with reference to patient feedback, including frequent opportunities to listen and act on views from less heard voices.

Patient Engagement

Patient engagement is defined as the desire and capability to actively choose to participate in care in a way uniquely appropriate to the individual, in cooperation with a healthcare provider or institution, for the purposes of maximizing outcomes or improving experiences of care

Improving Patient Engagement in Organ Transplantation: Recommendations for Best Practice (ISOU)

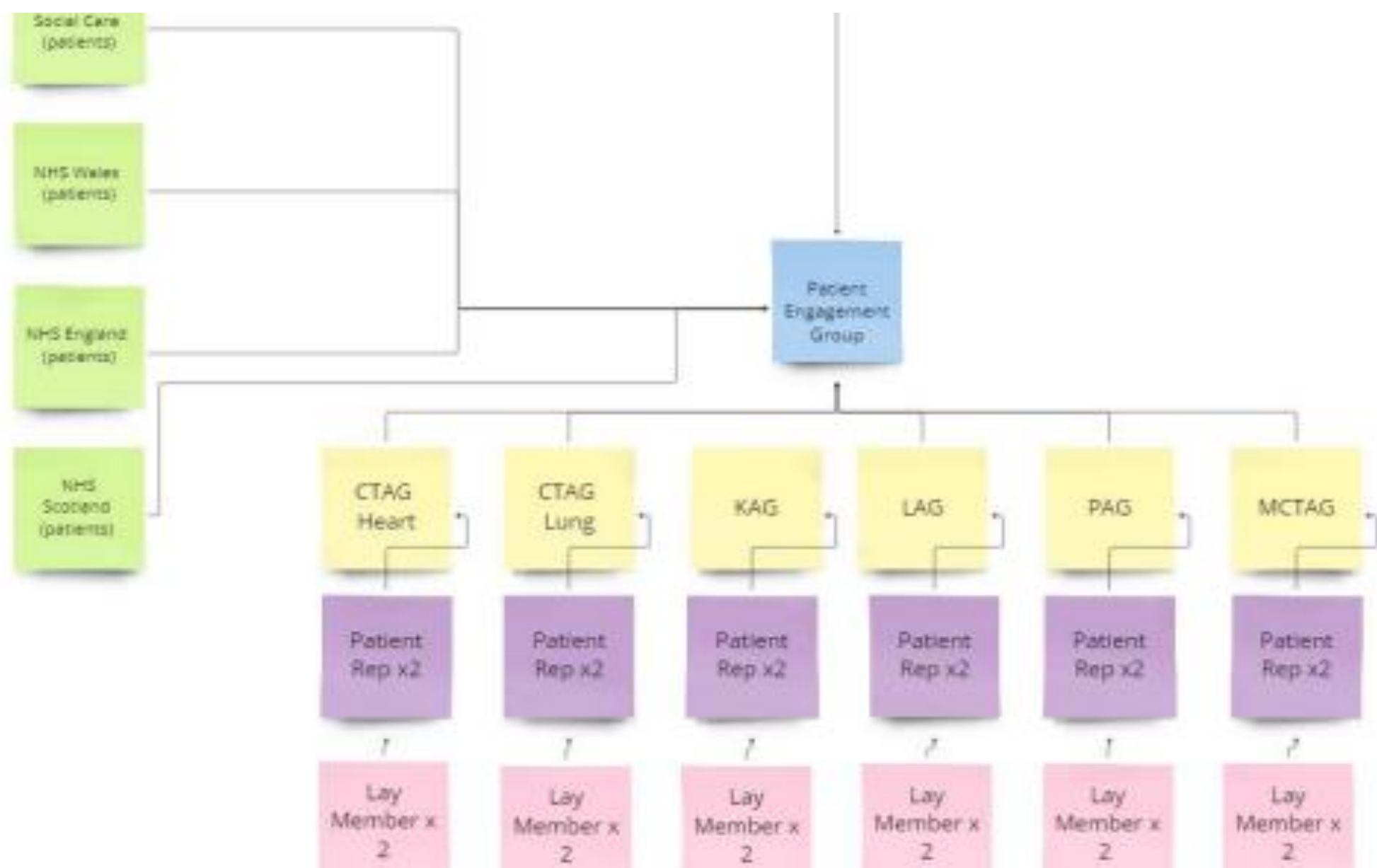
Core Membership

- Associate Medical Director for Patient Engagement OTDT (Co-Chair)
- Patient Partner (Co-Chair) Ann Gath
- Lead Nurse Recipient Co-ordinator (Deputy Chair)
- Patient Partners for each of the organ specific Solid Organ Advisory Groups that support the OTDT
- Transplant Development Leadership Team
- 2 OTDT Lay Members
- Other patient, public and professional representatives

Aims and Objectives

- Provide patient, carer and lay perspectives
 - Existing policies and services
 - proposed changes to policies and services
- Act as subject matter experts (SME)
 - Service improvement
 - Development initiatives
 - Advise on areas for service improvement, quality, safety, and accessibility
- Actively participate in co-production to design, deliver, and evaluate health services
- Recommend priorities for the AG's based on patient experience and feedback
- Engage in research design
- Co-production of future policies





PPAG work plan

- 3 broad themes with stems
 - Patient information
 - Website refresh (Pead's Liver section)
 - QR codes
 - Infographics/ risk tools
 - Improving patient experience
 - PROMs/PREMS
 - Trust engagement with local patient groups
 - ESIT remote clinics
 - Referrals for second opinions
 - Increasing waiting list engagement

Core themes

- Improve informed choice
 - Better clearer information
 - Readily accessible
 - Website development
 - Understandable
 - Responsive to clinical changes
 - Lay summaries
- Help trusts to appoint centre level leads in patient engagement
- Incorporation of PROM's and PREM's into clinical practice
- Co-production of services and research programs

Specific Requests for Advisory Groups

- 1. Review current content of websites
 - Consider developing Pead's section
- 2. Determine key components of remote clinics
- 3. Improve engagement with waiting list patients
 - Allocation policies
- 4. Review all other patient information
 - Infographics
 - Risk calculators
 - Consider unifying consenting information
- 5. Start examining how to facilitate improved patient mobility between centres