



Patient Insight Report

September 2024

Overview of the 3-year programme

Transform Advanced Kidney Care Core Team

Executive sponsor – Graham Lipkin
Medical lead – Rosie Donne
Project manager – Ranjit Klare
Admin support – Sarah Law

Apr 2024– Mar 2025

Understand the problem
& what good care is

Recruit 5 pilot renal units

Grow multidisciplinary
“community of practice”

Patients’ insights webinar
12/09/24

Professionals’ insights
webinar 26/11/24

Apr 2025 – Mar 2026

Develop & test the
AKC change package
and toolkit

QI training & support for
pilot renal units

MDT CoP contribute ideas to
change package

Apr 2026 – Mar 2027

Staff training to embed
change package, becomes
new standard of care

Staff training to embed
change package

MDT CoP attend training
events & webinars



Focus groups
Webinars
Face-to-face events
Comms to share learning





Patient Insight Event - 12th September 2024

46 Patients with recent experience of AKC Attended



[Introduction to the Transform AKC Programme - Rosie Donne](#)



AKC SLIDES

[Introduction to the Transform AKC Programme Slides - Rosie Donne](#)

[Next Steps - Ranjit Klare](#)



AKC Presentation



NEXT STEPS

Timings	Agenda	Speaker/ facilitator
2:00-2:05	Welcome and introductions	Rosie Donne, Programme Medical Lead
2:05-2:10	Introduction to the Transform AKC Programme	Rosie Donne
2:10-2:20	People living with kidney disease – a conversation	Ranjit Klare, Programme Manager with Hilary
2:20-3:05	Breakout room - “Your experience of AKC” Q 1. What worked well for you? Q 2. What can we improve on? Q 3. What felt/ feels important to you?	Facilitated by the KQIP Team
3:05-3:15	Comfort Break	
3:15-3:40	Feedback from the breakout rooms	Facilitators sharing key discussions
3:40-3:50	Next steps for the programme	Rosie Donne
3:50-3:55	Time to complete feedback form	Ranjit Klare
3:55-4:00	Closing remarks	Rosie Donne and Ranjit Klare



Key themes - what felt/feels important to you?

Family support	Bring family along to appointments; involved in the process; know what to expect
Accessible team with continuity of care	Personal contact, be honest and empathetic; not feeling rushed; not having to repeat my story; trust my team
Able to access blood results	Helps me to feel in control
Holistic services	Tailored to my needs, involve family, peer support, mental health support, access to renal social worker
Decision making	Being involved with the options, e.g. wanting PD instead of HD
Education about dialysis options	To see and touch dialysis equipment in person rather than just in a leaflet
Trusted information	Given at the right pace; list of things you will want to know; include "what-ifs"; things you can do to keep well
Symptom management	Knowing what symptoms mean for me



Key themes - what worked well for you?

Psychology support	Mental health support
Patient info	Facebook group, bitesize information, education days and bring family, meet other patients who have been through it
Family support	Attend appointments and education days, see equipment
Decision making	Feeling supported and having option to change mind
Support by staff	Getting to know me better. A phone call before AKC clinic to explain things
Appointment	Responsive to patient's needs/preferences, have easy contact for support or changes
Continuity of care	GP was involved, good communication between teams, renal team was single point of contact, patient support officer
Clear communication	Explain the good and bad news clearly; adapt language for patient and keep language simple, explain things and answer questions
Symptoms	Questionnaire in advance of appointment
Dietitians	Bring in early
Kidney care UK	Grant advice

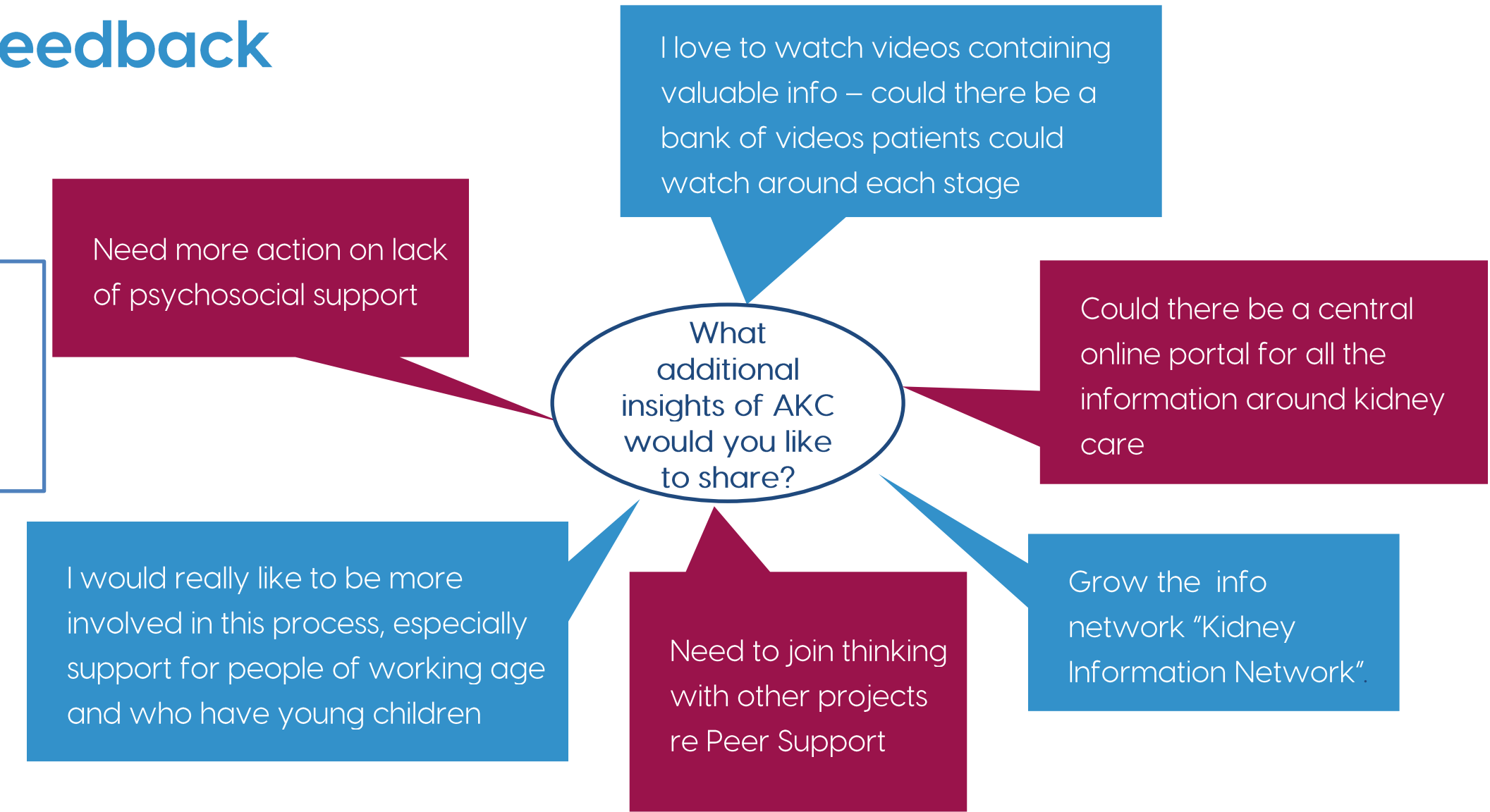
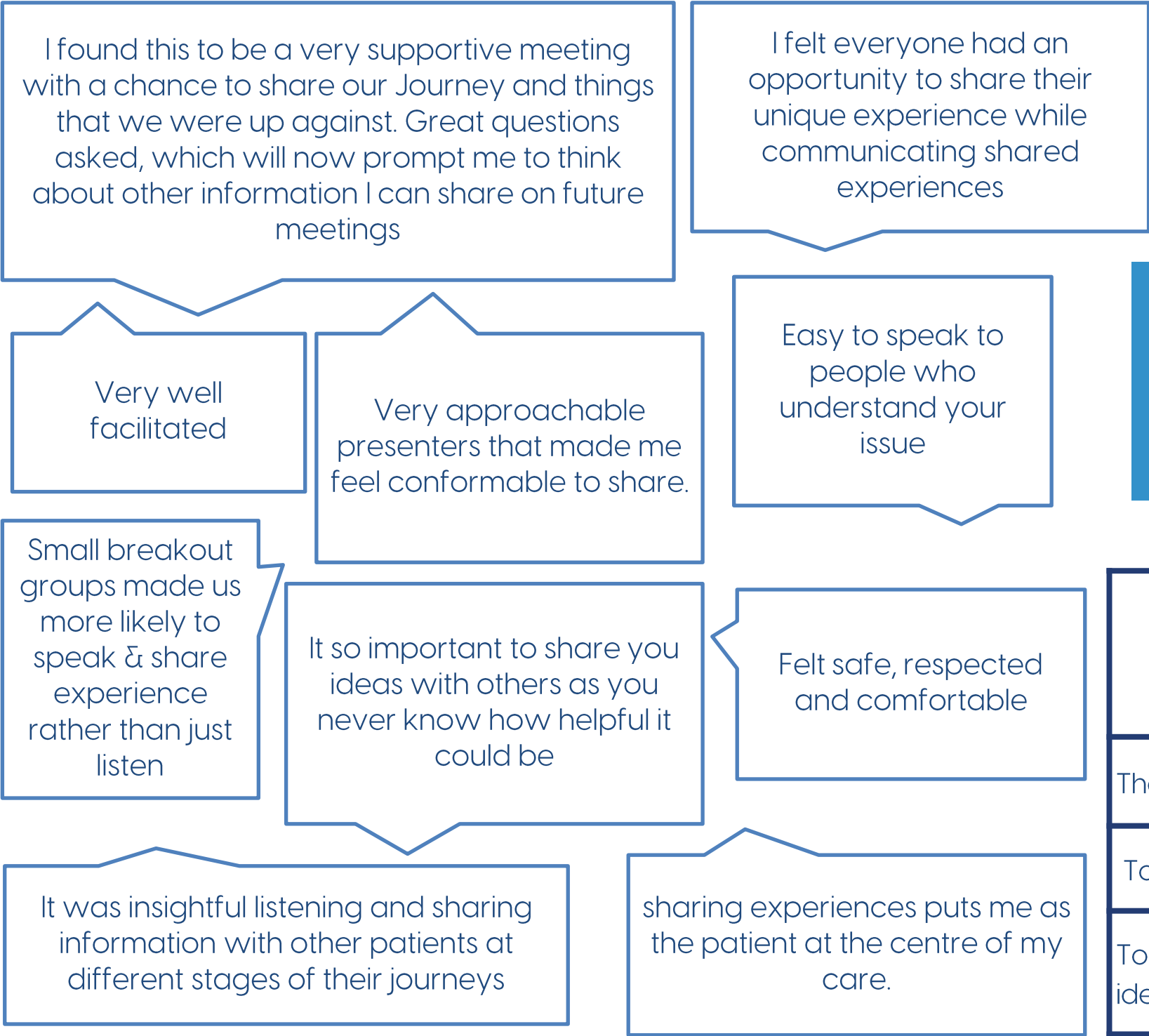


Key themes – what can we improve on?

Patient information	Flexible to patient's needs; ask patient about pace of info that patients want; consistent without information overload; explain pros and cons of treatment choices; tell patients what to expect; include families; transplant process (distress/waiting times); "need to know" checklist; hold regular patient info days; review treatment options when things are not going well – plan A, B & C; "top tips for being on dialysis"
Clinical appointment	What to expect; explain lifestyle changes to be made; timelines to plan with holidays; improve process for changing/cancelling appointments; reduce delays between clinic and GP changing prescription
Symptoms	Take time to listen to symptoms; pre appointment symptom checklist; explain side effects of treatment
Multiprofessional team	Early input from dieticians/social workers with in-depth discussions not just leaflets
Psychological support	Ask about mental health problems as it's difficult for patients to bring up; more mental health support; helping with denial
Staff training	Active listening skills; not to make assumptions on treatment choices; involve patient in decision making; support before AKC clinic; better education of GPs and their staff about needs of kidney patients
Continuity of care	See the same staff (nurses/doctors/dieticians) helps to build trust, communication between GP and renal team
Family support	Encourage to bring family to appointments & education, ask questions; help family to know what to expect
Support groups	Peer support/buddying/patient education days/F2F peer support
Ethnic diversity	Cultural appropriation and specific tailored information
Patient empowerment	Track blood results myself; patients can ask what the next steps are and have contact details for key people
Non-clinical worries	Finance / benefits / work/ equalities and disabilities act



After-event feedback



We asked those who attended to rate their experience out of 5 (1 = not very good and 5 = very good). These are the average score results:	
The overall experience of the meeting	4.67
To what extent did this meeting promote patient involvement in the quality improvement project?	4.71
To what extent did this meeting enable you to build positive relationships, collaborate and share ideas with others?	4.46

Next steps



- **Project team identify themes** for further focus
- **Present themes** at professionals' webinar 26 November 2024
- **Focus groups to explore themes in more detail**
- **Attend F2F event 25 March 2025** - Birmingham
 - **volunteers needed** to help lead a workshop on "What is important to patients"
- Help with future codesign of change package
- Attend workshops/webinars in years 2 & 3
- **Email: ranjit.klare@ukkidney.org**



Additional Links

Dela Idowu – GOLD Peer buddy scheme

[GOLD – Telephone Buddy Scheme \(giftoflivingdonation.co.uk\)](http://giftoflivingdonation.co.uk)

Hilary Rose – Workshop For People with CKD, Chronic Illnesses & Disabilities

kwll.co.uk

Keith Bucknall - Think?Transplant video

[Think?Transplant \(youtube.com\)](https://www.youtube.com/watch?v=...)