



# Professionals Insight Report

## November 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

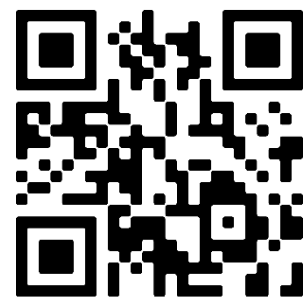


Focus groups  
 Webinars  
 Face-to-face events  
 Comms to share learning





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



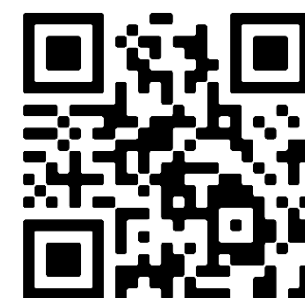
AKC Presentation

[Professionals Insight Webinar Slides - Rosie Donne](#)



Professionals Webinar Slides

[Patient Perspective: Linda](#)



Patient Perspective

## Professionals Insight Event - 26th November 2024

**144** Professionals and patients with recent experience of AKC Attended

Time	Session			
14.00 5 mins	Welcome & plan for today Rosie Donne, KQIP Clinical Co-Lead			
14.05 10 mins	Transform AKC presentation Rosie Donne, KQIP Clinical Co-Lead			
14.15 10 min	Patient presentation – what was good during AKC and what could have been improved			
14.25 10 min	Summary of learning from patient insight webinar Ranjit Klare, KQIP Programme Manager			
14.35 15 mins	Presentation of pre-webinar questionnaire themes Rosie Donne, KQIP Clinical Co-Lead			
	Each attendee goes to 3 breakout rooms to discuss: a) what is ideal b) what is often missing / suboptimal			
14.50 30 mins	Breakout room 1a Symptom management Dr Sabine van der Veer & Prof. Derek Kyte	Breakout room 1b Shared decision making / communication Dr Anna Winterbottom	Breakout room 1c Patient education Laurie Cuthbert, KCUK	Breakout room 1d Service design & delivery Dr Rosie Donne
	Breakout room 1e Psychosocial support Emma Coyne	Breakout room 1f Peer support Eleri Wood	Breakout room 1g Multi- professionals input (dietician/OT/PT) Lisa Ancliffe	Breakout room 1h Live donor transplant Dr Richard Powell
	15.20 Comfort break (10 mins)			
15.30 30 mins	Breakout room 2 Same as in 1a-h	Breakout room 2	Breakout room 2	Breakout room 2
16.00 30 mins	Breakout room 3 Same as in 1a-h	Breakout room 3	Breakout room 3	Breakout room 3
16.30 25 mins	Feedback from breakout rooms (3-4 mins from each room)			
16.50 5 mins	Evaluation & next steps Rosie Donne, KQIP Clinical Co-Lead			

## Key themes

Service delivery models

Patient education

Shared decision making (SDM)

Symptoms detection

Allied health professional (AHP) support

Live donor transplant

Psychosocial care

Peer support

## Key themes – Examples of ideal care

Theme	Examples of ideal care
Service delivery models	<ul style="list-style-type: none"> <li>Full MDT model of AKC – core dedicated staff</li> <li>Continuity of care</li> <li>Equity across wide geographical area</li> <li>Full choice of treatment modalities</li> <li>Target resources towards those at most need Blood tests close to home, access results</li> </ul>
Patient education	<ul style="list-style-type: none"> <li>AKC nurse home visits</li> <li>Group patient education days / roadshows</li> <li>Peer supporters at education days</li> <li>Family included</li> <li>Variety of resources (paper / digital)</li> </ul>
Shared decision making (SDM)	<ul style="list-style-type: none"> <li>Staff get to know the patient holistically</li> <li>Discuss social/family/work issues</li> <li>Dedicated appointment(s) for SDM</li> <li>Find out what matters most to the patient</li> <li>Communication tailored to the patient</li> <li>Decision aids / videos / leaflets</li> <li>Honest communication about dialysis</li> </ul>
Symptoms detection	<ul style="list-style-type: none"> <li>Ask patient about common symptoms, give time to explain and give support</li> <li>iPOS / ePROMs before / during appointment</li> <li>Patients report worsening symptoms between appointments, advice given</li> <li>Signpost to resources (videos/leaflets)</li> </ul>



## (Cont'd) Key themes – Examples of ideal care

Theme	Examples of ideal care
Allied health professional (AHP) support	<ul style="list-style-type: none"> <li>All skills available within AKC team</li> <li>Proactive not reactive approach</li> <li>AHPs attend patient education days</li> <li>Geriatrician / frailty service</li> <li>Signposting to available local support</li> </ul>
Live donor transplant	<ul style="list-style-type: none"> <li>Early education about future transplant</li> <li>Culturally relevant education</li> <li>Events to raise awareness on living donation</li> <li>Home visits to discuss living donation</li> <li>One-stop workup pathways</li> </ul>
Psychosocial care	<ul style="list-style-type: none"> <li>MDT trained to identify needs</li> <li>Psychosocial conversations toolkit</li> <li>Routine psychosocial needs screening</li> <li>Ask about mental health symptoms proactively</li> <li>Refer to renal psychologist / counsellor</li> <li>Signpost to charity support</li> <li>Young adults service</li> <li>Cultural liaison officer</li> </ul>
Peer Support	<ul style="list-style-type: none"> <li>Large pool of peer supporters</li> <li>Good matching - patient and supporter</li> <li>Peer support training programme</li> <li>Informal gatherings / drop-ins</li> <li>Individual and group support options</li> <li>Support for carers</li> </ul>



## Key themes – what are the barriers to providing ideal care?

Theme	Barrier to providing ideal care?
Service delivery models	Geographical inequities in provision of MDT care Increasing demands, lack of expansion Increasingly complex / comorbid patients Lack of referral criteria High DNAs – socioeconomic problems, language Surgical bottlenecks
Patient education	Language, cultural, health literacy Access to technology for digital resources Access to paper resources Lack of staff time Delayed referral for education
Shared decision making (SDM)	Language, cultural and health literacy Lack of knowledge on signposting to information Lack of time for high quality SDM Inconsistent messages from different team members Negative experiences of family/friends cause bias Lack of patient confidence for home therapies
Symptoms detection	Patients don't know if symptoms are due to CKD Patients forget to tell symptoms during appointment Poor treatment evidence/efficacy Knowing what GP vs. hospital should manage Lack of signposting to support and information



## Key themes – what are the barriers to providing good care?

Theme	Barrier to providing ideal care?
Allied health professional (AHP) support	<ul style="list-style-type: none"> <li>Lack of funding for all AHP members</li> <li>Having to collect data and write business case</li> <li>OT/PT struggle to arrange support no social worker</li> <li>No benchmarking of what is needed / best practice</li> </ul>
Live donor transplant	<ul style="list-style-type: none"> <li>Lack of patient education on potential donors</li> <li>Lack of priority for recipient / donor workup tests</li> <li>Multiple appointments – DNAs</li> <li>Lack of admin support to streamline pathway</li> <li>Lack of theatre capacity</li> </ul>
Psychosocial care	<ul style="list-style-type: none"> <li>Increasing burden of mental health problems</li> <li>Limited AKC appointment time</li> <li>Lack of staff confidence for conversations</li> <li>Long wait for psychology support</li> <li>Lack of psychosocial staff and funding</li> <li>Lack of clinical leadership on psychosocial support</li> <li>Lack of knowledge of available support</li> <li>Difficulty engaging with certain groups</li> </ul>
Peer support	<ul style="list-style-type: none"> <li>NHS trusts' peer support training requirements</li> <li>Lack of structure for peer support programme</li> <li>Resource and time to run support programme</li> <li>Lack of support for peer supporters</li> <li>Clinicians don't promote peer support service</li> <li>Lack of peer support role models</li> </ul>





## After-event feedback

Liked the opportunity to participate in 3 breakout rooms - so this type of thing again would be great

Excellent to hear patients and their thoughts - more of this please!

More time to discuss different elements, maybe more prescribed / matched groups to help share or deepen knowledge

More focus on the ideal transplant pathway from AKC please

I think I may have contributed a bit more if I had been in a face-to-face session

What additional insights of AKC would you like to share?

Great session

Great afternoon, very interesting, thought provoking.

I enjoyed the patient/MDT involvement. It felt natural and useful rather than forced.

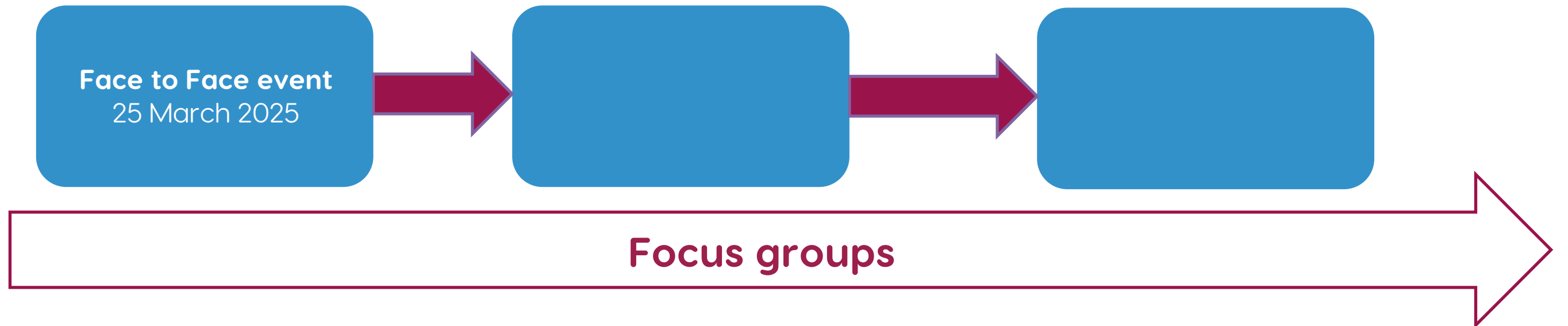
Excellent webinar. Good variety of topics covered with very knowledgeable leaders. Thanks

Excellent programme

**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	4.36
To what extent did this event enable you to collaborate and share ideas with others?	4.35
To what extent did this event promote patient involvement?	4.23
To what extent did this event promote a collective learning environment among the multi-professional team?	4.42

## Next steps



- **Project team identify themes** for further focus
- **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](mailto: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](http://kwll.co.uk)

**Keith Bucknall - Think?Transplant video**

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