



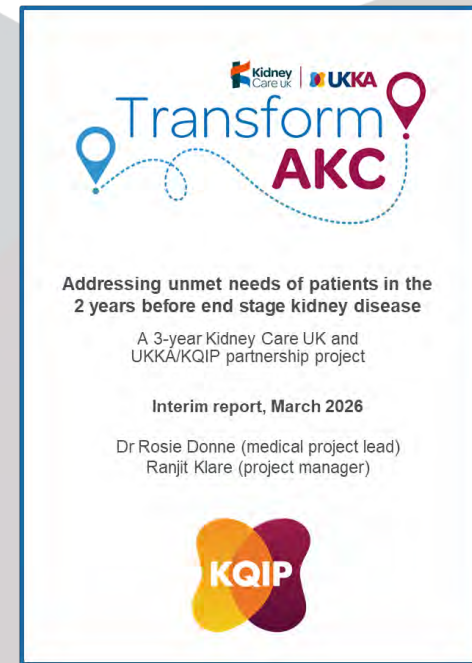
# Transform AKC

For the best patient experience

## Transform AKC Summit - 12 May 2026

**Mission – to address unmet needs of patients in the 2 years before expected to reach end stage kidney disease**

A Kidney Care UK and UKKA/KQIP partnership project, June 2024 - 2027



# Welcome to...



- People living with Kidney disease
- Healthcare professionals and researchers
- Guest speakers and facilitators
- Transform AKC pilot renal units
  - Kilmarnock, Bradford, Nottingham, Stevenage, London Royal Free
- Kidney Care UK partners
- Kidney charities
- Event sponsors

**CSL Vifor**

AstraZeneca

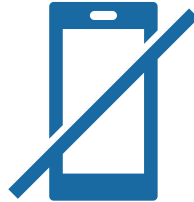
**MEDICE**  
THE HEALTH FAMILY

**STADA**  
Tharnton & Ross

# Housekeeping



No planned  
Fire alarms



Phones  
on silent



Speak to team  
if concerned about  
social media



Lunch break  
12.45 - 13.45



**Wifi** - The Studio offers complimentary Wi-Fi access throughout the premises.  
To connect, simply open your browser and sign up by providing your email address.

# Morning programme



09.30 – 09.50 **Transform AKC – Welcome – Dr Rosie Donne, Project lead**

09.50 – 10.00 **Patient Focus Group – Teresa Davy (Co-chair)**

10.00 – 11.00 **Keynote speakers**

## **Timing and risk prediction of KFRE**

Dr Rupert Major, Consultant Nephrologist, Leicester

## **Beyond Restriction: The Role of Diet in Advanced Kidney Care**


Dr Sharon Huish, Advanced Practice Renal Dietitian, Royal Devon

## **Making the most of the AKC consultation – bridging the health literacy gap**

Joanne Henry, Lead nurse Hypertension & CKD, Royal Free London

11.00 – 11.15  coffee break (4<sup>th</sup> Floor)

11.15 -12.45 **World Café session**  
Bradford, Kilmarnock, Nottingham, Royal Free, Stevenage • KCUK • Patient Focus Group

12.45 –13.45  lunch 4<sup>th</sup> Floor (+ healthcare professionals meet sponsors)

# Afternoon programme

13.45 – 14.35 Choose parallel interactive workshop 1

<p><b>How people make choices/ shared decision-making</b> Room: Connect (floor 4) Dr Anna Winterbottom Dr Jyoti Baharani</p>	<p><b>Smooth transition onto home dialysis</b> Room: Develop (floor 3) Dr Mark Lambie Julie Oliver &amp; Elaine Gibson</p>	<p><b>Transplant workup pathways - new BTS guideline for cardiac assessment</b> Room: Innovate (Main Room, floor 3) Prof Adnan Sharif Dr Shivanand Chavan</p>
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14.35 – 14.45  tea/coffee break

14.45 – 15.35 Choose parallel interactive workshop 2 (as above)

15.35 – 16.25 Choose parallel interactive workshop 3 (as above)

16.25 – 16.30 Next steps, feedback & close



# Transform AKC

For the best patient experience

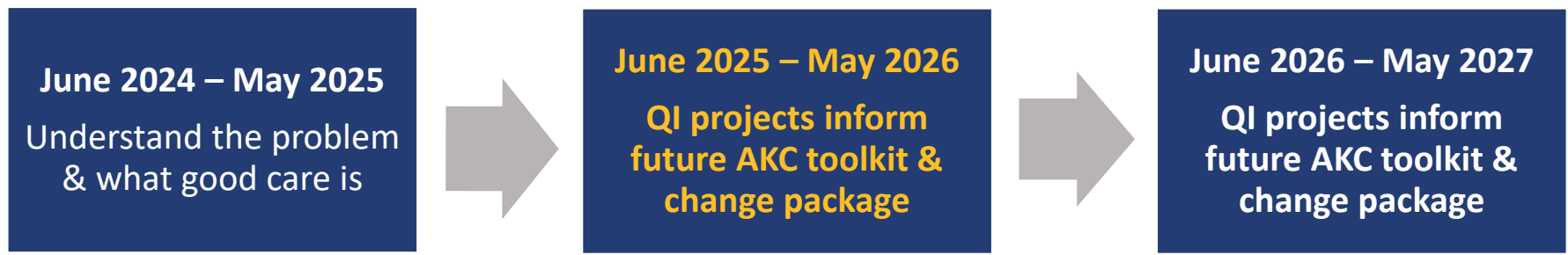
**Transform AKC Summit - 12 May 2026**

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# 3-year project overview

We are here  
↓



Recruit 5 pilot renal units

Gather insights from AKC patients

AKC staff share insights

Literature review of evidence-based multidisciplinary interventions in AKC



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**June 2024 – May 2025**  
Understand the problem & what good care is

Recruit 5 pilot renal units

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AKC staff share insights



**June 2025 – May 2026**  
QI projects inform future AKC toolkit & change package

KQIP training & support for pilot renal units

Integral AKC patient focus group

Shared learning via webinar and summit



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**June 2026 – May 2027**  
QI projects inform future AKC toolkit & change package

KQIP training & support for pilot renal units

Integral AKC patient focus group

Staff training to embed AKC change package

Spread and sustainability planning

Literature review of evidence-based multidisciplinary interventions in AKC



# Key messages about ideal AKC from patients and staff



Ensure care is **timely**



**Understand the individual**  
person's needs and  
preferences



**Tailor care** to the individual,  
ensure equity

# What does peer-reviewed literature tell us about best practice?

# Literature review - Multidisciplinary interventions in AKC

## What evidence is there on effectiveness and patient experience of multidisciplinary care in adults with non-dialysis advanced CKD?

- service delivery models
- patient assessment tools, educational approaches, shared decision making
- other non-pharmaceutical interventions to improve outcomes

## Caveats about quality of evidence:

- Very few randomised controlled trials
- “multidisciplinary care” was variable between reported studies
- Small patient numbers
- Short follow-up period
- Varying outcome measures
- Some studies included earlier CKD stages – sometimes difficult to separate results
- Lots of gaps (e.g. ethnicity, health literacy, health economics)

8,000



**121 articles**

**Scoping review**

Thank you to:

Robert Kimmitt  
 Hugh Leonard  
 Oshini Shivakumar  
 Helen Hurst  
 Anna Winterbottom  
 Karen Storms  
 Rebecca Stansfield

# AKC interventions with evidence

## Multidisciplinary care with SDM

18 months+  
Cost savings  
3+ disciplines needed

Data tracking of patient progress  
+ targeted actions

## Risk prediction tools

Mortality  
KFRE  
disease-specific for IgAN & PKD

## Patient Reported Outcome Measures (PROMs)

Symptoms  
Starting dialysis Q

## Patient education variety of methods

Build health literacy  
Peer mentors

## Structured shared decision making

Involve family  
Decision aids, groups  
Staff training

## Psychosocial support

Improved depression, anxiety and adherence  
Social worker – key role

## Personalised dietetic advice

Slow progression  
Improve QoL

## Comprehensive geriatric assessment

Person-centred goals  
Improved SDM

## Exercise programmes

Aerobic  
Resistance  
Improved QoL

## Integrated palliative care support

Surprise question  
Advanced care planning

## Renal pharmacist

Improve adherence  
Reduce side effects  
Address polypharmacy

# Pilot renal unit QI projects

Find out more in the World Café session, 11.15 - 12.45



Health literacy – Royal Free, London



Frailty - Kilmarnock



Symptoms detection and management - Nottingham



Patient education and shared decision making - Bradford



Pre-emptive transplant - Stevenage



**How can we make sure all patients receive trusted, accessible information?**

# What patients said about receiving information in AKC clinic





# AKC patient information folder pilot

## New AKC patients at pilot sites




Share your thoughts about this pack


# My kidney journey



Practical information



Top tips



Keep your notes together

### Get ready for your appointment

- Bring a family member or friend to your appointments to help you understand or speak up for you if needed.
- Make a note of how you are feeling physically and emotionally, so you can talk about it to your doctor during your appointments.
- Bring a list of your medications with you.
- Find out how to access your blood results.
- Before your appointments, write down questions to ask on the day.
- Check your blood pressure often and bring the readings to your appointments.

### Things you can do to stay well



- Find out more about your kidney problems from talking to staff, other patients, recommended websites and leaflets.
- Support your physical and mental wellbeing with regular, light exercise such as walking, swimming, gardening, exercise classes in a leisure centre or online at home.
- Join a local or online support group to connect with other kidney patients and learn more about your condition.
- Take your medications as prescribed.
- Eat well – avoid highly processed foods, reduce salt intake and follow any specific dietary advice.

### Notes

Kidney Care UK leaflets inside pocket

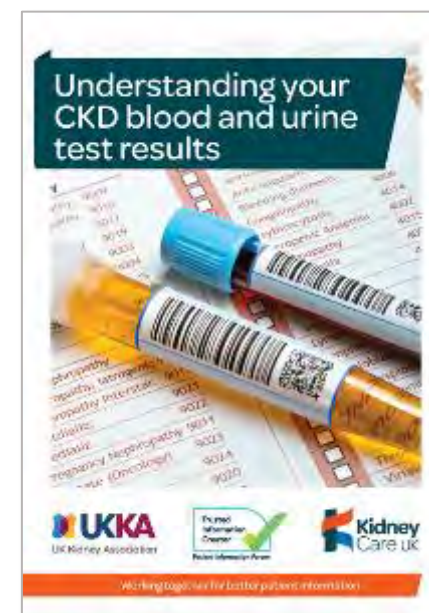
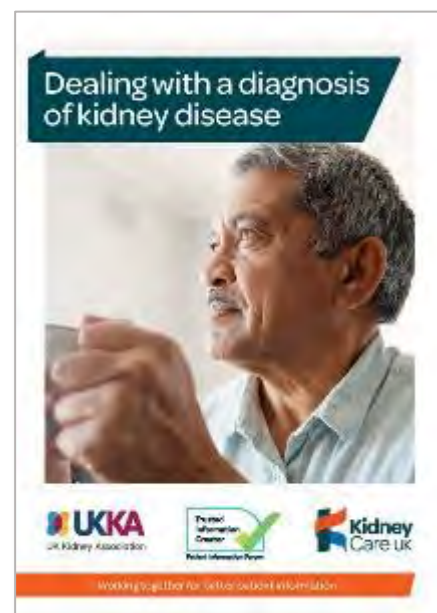
### Don't forget!

- Check your blood pressure often and record the results.
- Ask your unit how to track your blood test results.
- You can access translated information online in over 100 languages - visit [kidneycareuk.com/AKC-translate](https://www.kidneycareuk.com/AKC-translate) or scan the QR code.



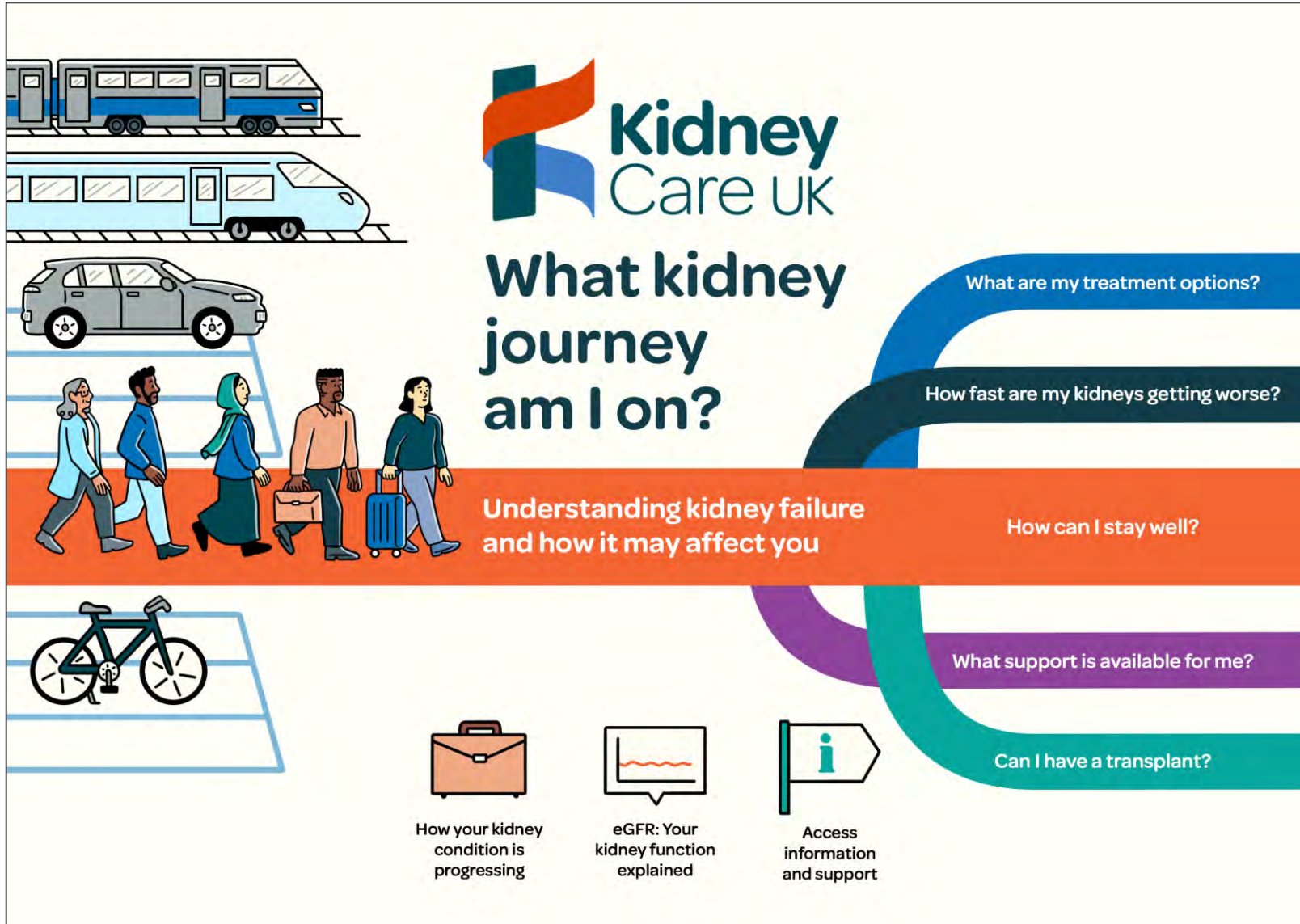
Our mission is to improve the quality of life for everyone affected by kidney disease. Our trained team are on hand to talk about all aspects of living with kidney disease and the practical, emotional and financial support we can offer. Please get in touch.

# Patient information leaflets included in folder



Introductory information to help explain AKC, but without overwhelming.  
Ensure all patients are aware of Kidney Care UK and support available

# Includes graphical illustrations of kidney journeys



**Kidney Care UK**

## What kidney journey am I on?

Understanding kidney failure and how it may affect you

What are my treatment options?

How fast are my kidneys getting worse?

How can I stay well?

What support is available for me?

Can I have a transplant?

How your kidney condition is progressing

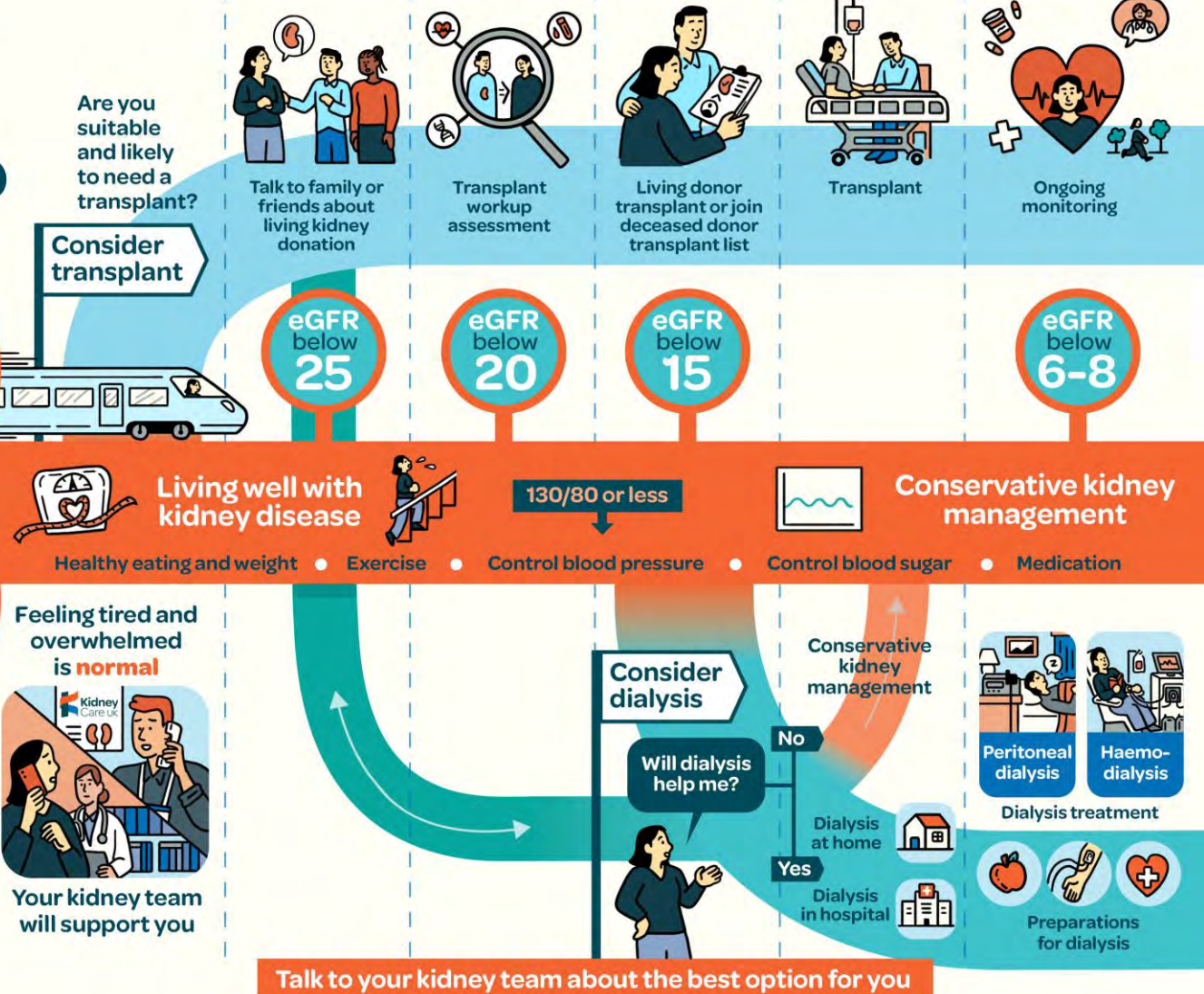
eGFR: Your kidney function explained

Access information and support

# Rapidly failing kidneys (except due to type 1 diabetes)



Talk to other people who are living with kidney disease



## Low but stable kidney function



eGFR below 15

Discuss options



Discuss dialysis and/or transplant if kidney function worsens or if you would like to know more (see other pathways)

### Living well with kidney disease



Healthy eating and weight



Exercise



Control blood pressure



Control blood sugar



Medication

### Conservative kidney management

Talk to other people who are living with kidney disease

Talk to your kidney team about the best option for you



## Integral AKC patient focus group

**“A diverse community of about 20 people with recent or current lived experience of advanced kidney care”**

- Ensure patient perspectives are at the centre of the projects
- Participate in all project events
- Review patient information resources
- Informal peer support group

Promote  
positive  
change

A safe  
space

# Patient Focus Group

Teresa Davy  
Co-chair



# Keynote Speakers

## **Timing and risk prediction of KFRE**

Dr Rupert Major, Consultant Nephrologist, Leicester

## **Beyond Restriction: The Role of Diet in Advanced Kidney Care**

Dr Sharon Huish, Advanced-Practice Renal Dietitian, Researcher & Service Lead, Royal Devon

## **Making the most of the AKC consultation – bridging the health literacy gap**

Joanne Henry, Lead nurse Hypertension & CKD Royal Free London

# World Café session 11:15-12:45

## Instructions

**10-12 minutes at each table**

**Bradford, Kilmarnock, Nottingham, Royal Free, Stevenage**

**Kidney Care UK • Patient Focus Group**

Your Name badge will have a letter ABCDEFG – this will be your starting point

# Coffee break – back 11.15



Grab a coffee and check out the industry room – 4<sup>th</sup> Floor



# Lunch break

Grab some lunch and check out the industry room – Room BOND 4<sup>th</sup> Floor



## First interactive workshop 13.45 – 14.35

<p><b>How people make choices/ shared decision-making</b> Room: Connect (floor 4) Dr Anna Winterbottom Dr Jyoti Baharani</p>	<p><b>Smooth transition onto home dialysis</b> Room: Develop (floor 3) Dr Mark Lambie Julie Oliver &amp; Elaine Gibson</p>	<p><b>Transplant workup pathways - new BTS guideline for cardiac assessment</b> Room: Innovate (Main Room, floor 3) Prof Adnan Sharif Dr Shivanand Chavan</p>
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# Tea break



## Second interactive workshop 14.45– 15.35

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**Thank you to all our guest speakers,  
facilitators, patients and Kidney Care  
UK**

# Next steps...

- **Pilot site projects ongoing**
- **Pilot use of new AKC patient information pack (Feb-July 2026)**
- **Webinar Autumn 2026** focusing on key skills in AKC
- **Develop UKKA knowledge hub page** – AKC toolkit from pilot site projects
- **Work on how to spread and sustain** project learning
- **Pdfs of slides will be emailed on completion of feedback**

## Feedback



For more information  
[Ranjit.Klare@UKkidney.org](mailto:Ranjit.Klare@UKkidney.org)