



For the best patient experience

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

Dr Rosie Donne, KQIP Clinical Co-lead, UKKA

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Laurie Cuthbert, Director of Fundraising, Marketing and Communications, Kidney Care UK

Welcome to...



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

CSL Vifor

AstraZeneca 

 **MEDICE**
THE HEALTH FAMILY


STADA
Thornton & Ross
STADA 10000000

Baxter

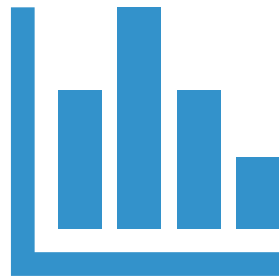
Our mission



- Understand ideal AKC
- Understand unmet needs of people receiving AKC
- Upskill the AKC workforce to provide better, holistic care
- Measure patient progress and outcomes to drive improvement



Enable spread of
best AKC practice



Address variation
in AKC care

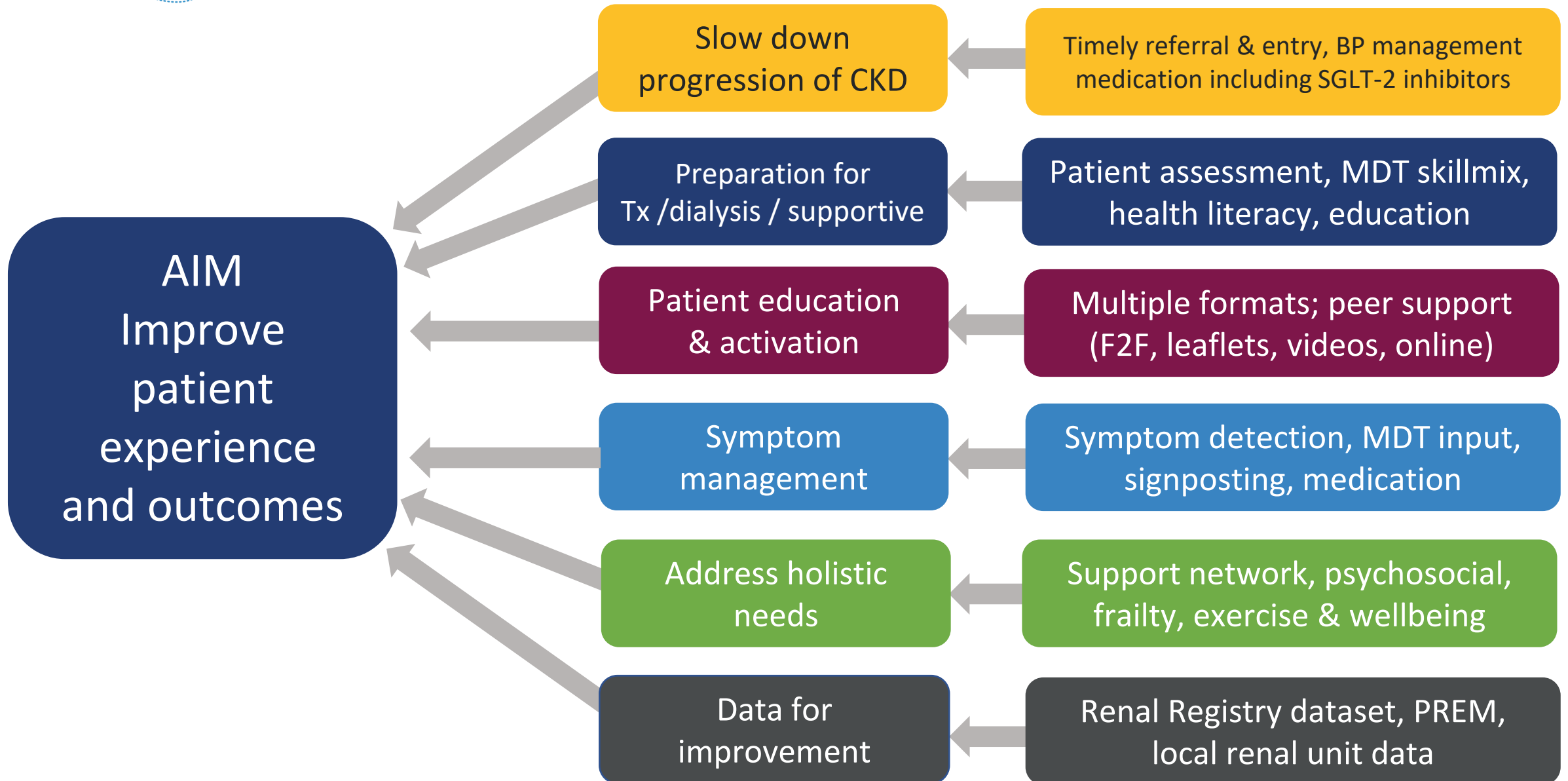


Better patient
experience and QoL



Reduce unnecessary
hospital contact

AKC themes



Project stages

Year 1
2024-25

Understand ideal care and barriers to providing it
Recruit 5 pilot renal units onto quality improvement (QI) programme

Year 2
2025-26

5 pilot renal units perform different QI projects

- develop elements of AKC change package and toolkit

Year 3
2026-27

QI projects ongoing + staff training to embed change package

- AKC change package becomes the new standard of AKC care
- Recommendations for “value-based” AKC commissioning to support spread

**Active
group of
patients
and carers**



**Shared
learning**

Year 1 (April 2024 – March 2025)

Understand ideal care and barriers

Patients & carers actively involved throughout

Recruit
patient
participation
group

Patients'
insights
webinar
September
2025



Recruit
5 pilot renal
units



Professionals'
insights
webinar
November
2025



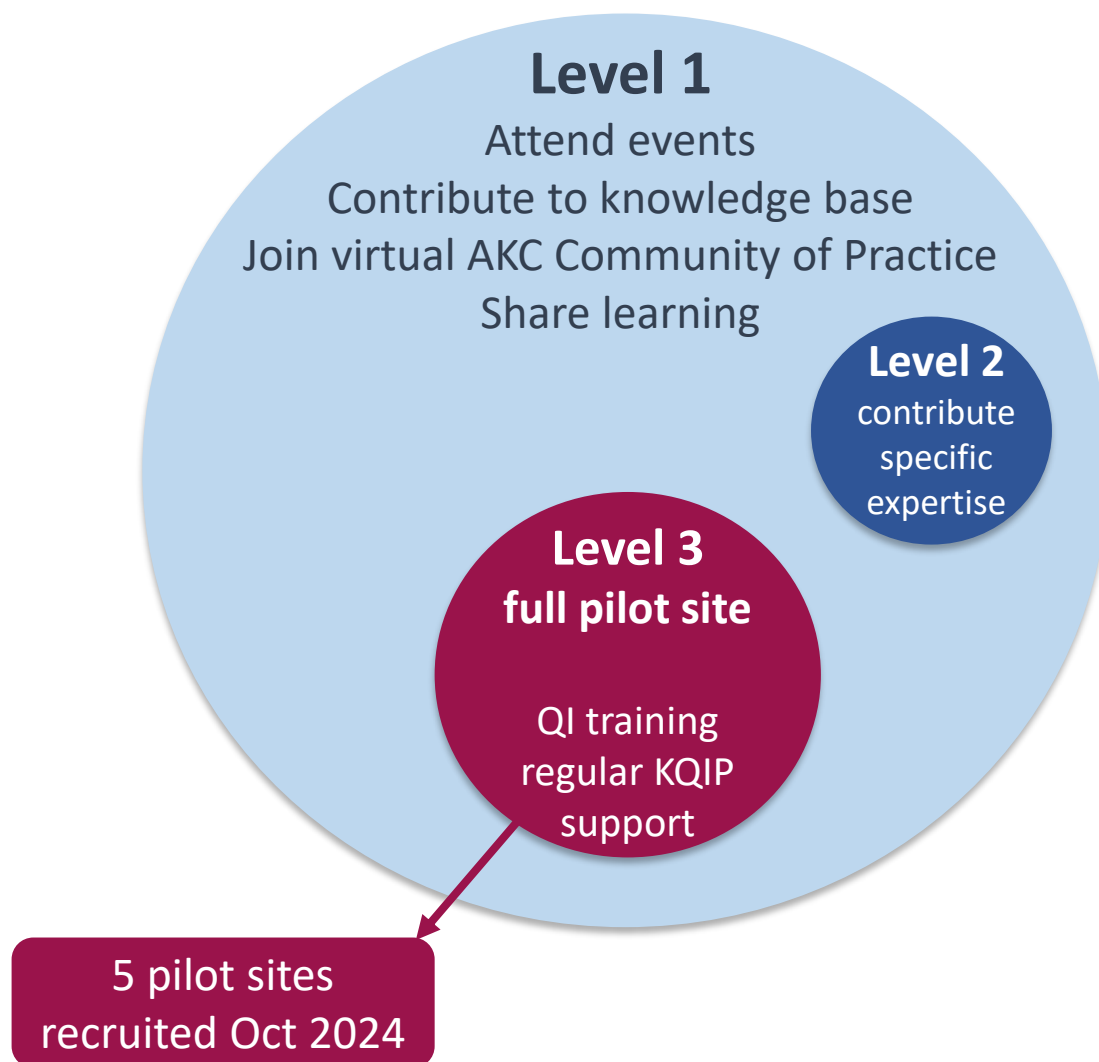
Transform
AKC Summit
Birmingham
25 March
2025



Grow multidisciplinary “AKC community of practice”

Review of published evidence of interventions to improve AKC

Transform AKC MDT Community of Practice



Join the Transform AKC Community of Practice here:



for more info – Ranjit.Klare@UKkidney.org

Patient Insights webinar September 2024

What feels/felt most important to you during AKC?

Honest team I
can trust &
contact easily

Not having to
repeat my story

Feel fully
involved in
decision making

Family able to
attend
appointments

Understanding
about
symptoms

Seeing my blood results online

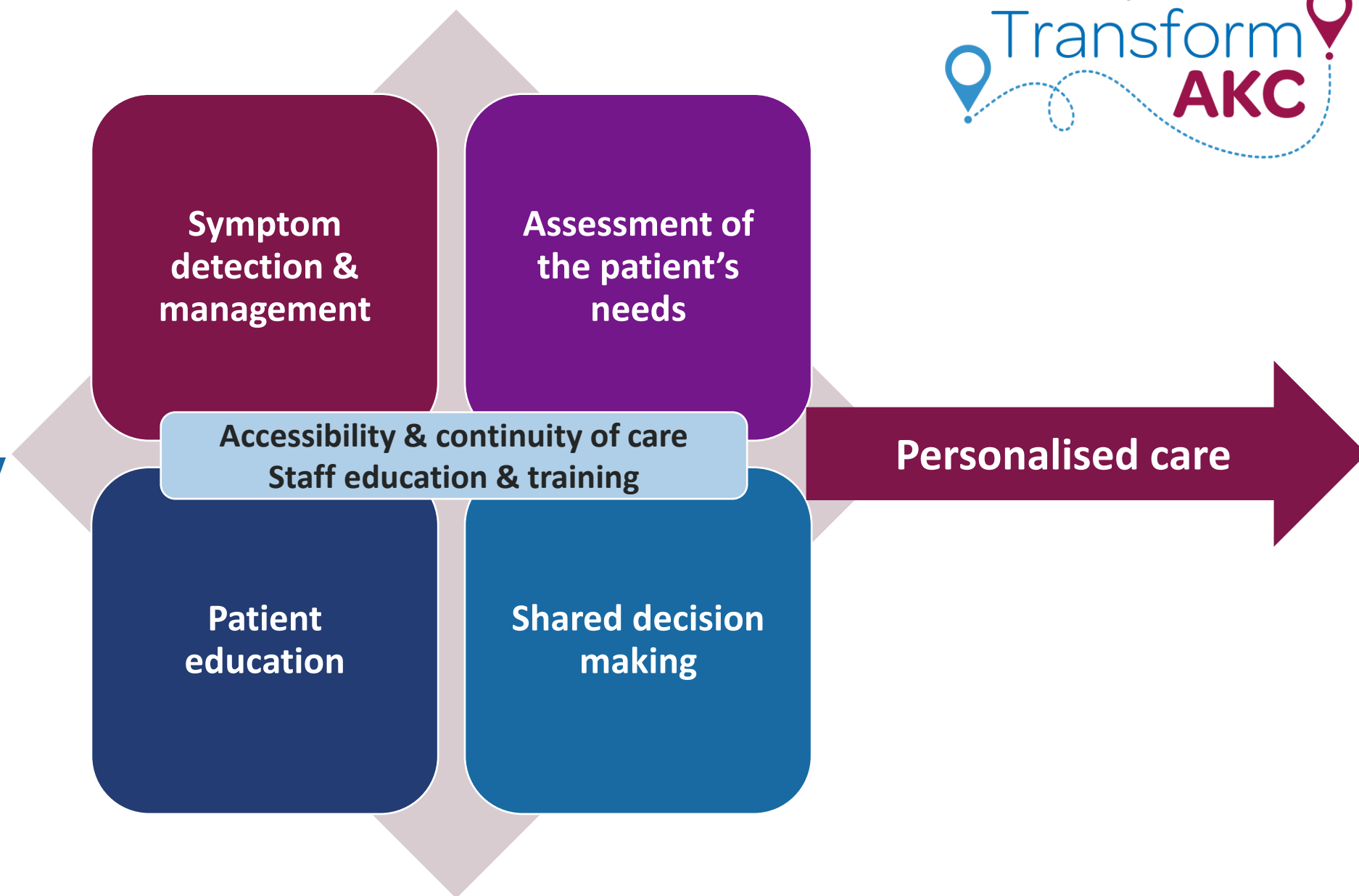


Meet other people with
experience of kidney
treatments

46 patients attended
patient insights webinar

Patient insights webinar

"Ideal care" themes



September 2024

Symptoms

- Ask about symptoms
- Use checklists
- See & understand blood results
- Access to dietitian

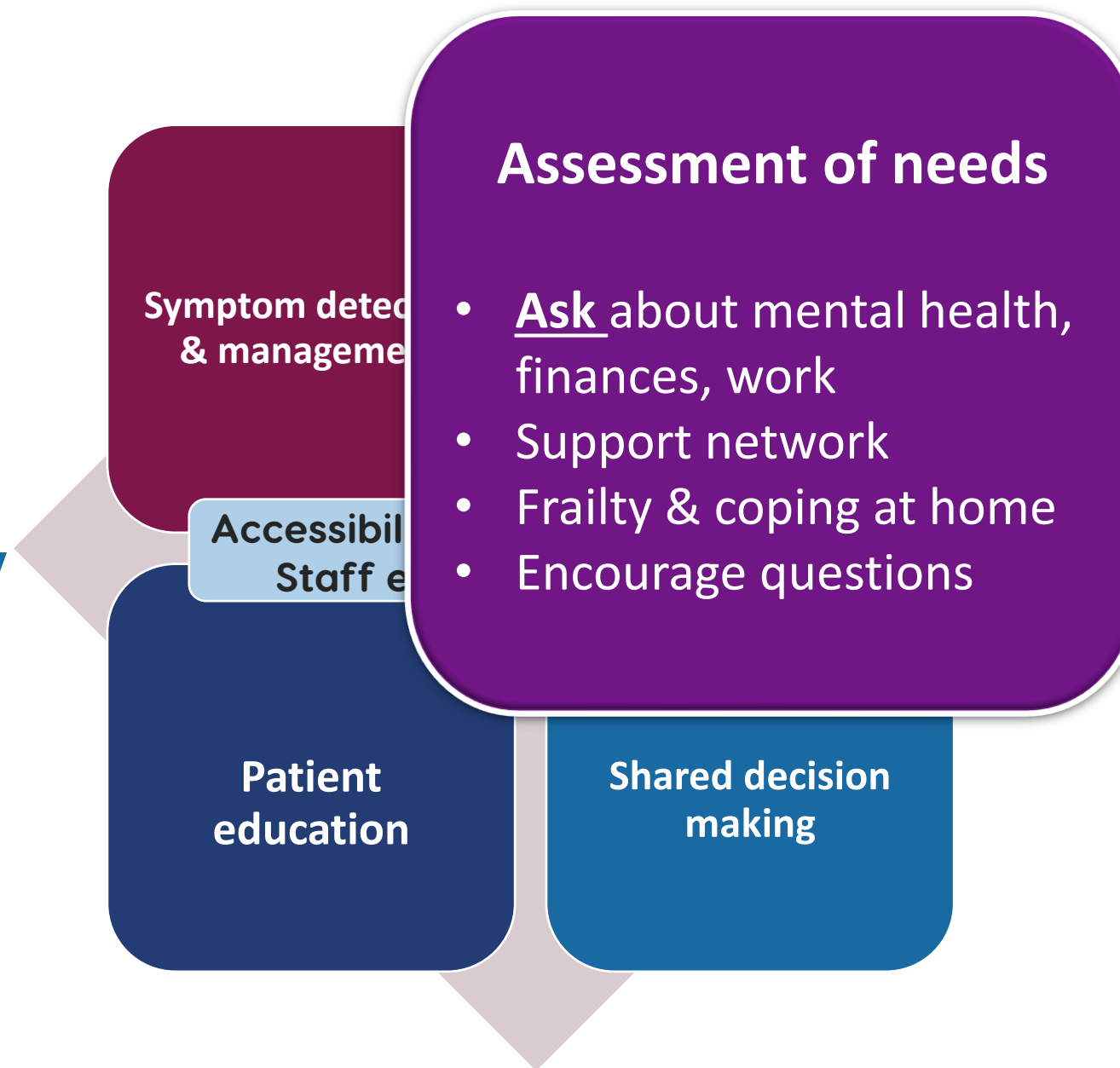
Assessment of
patients' needs

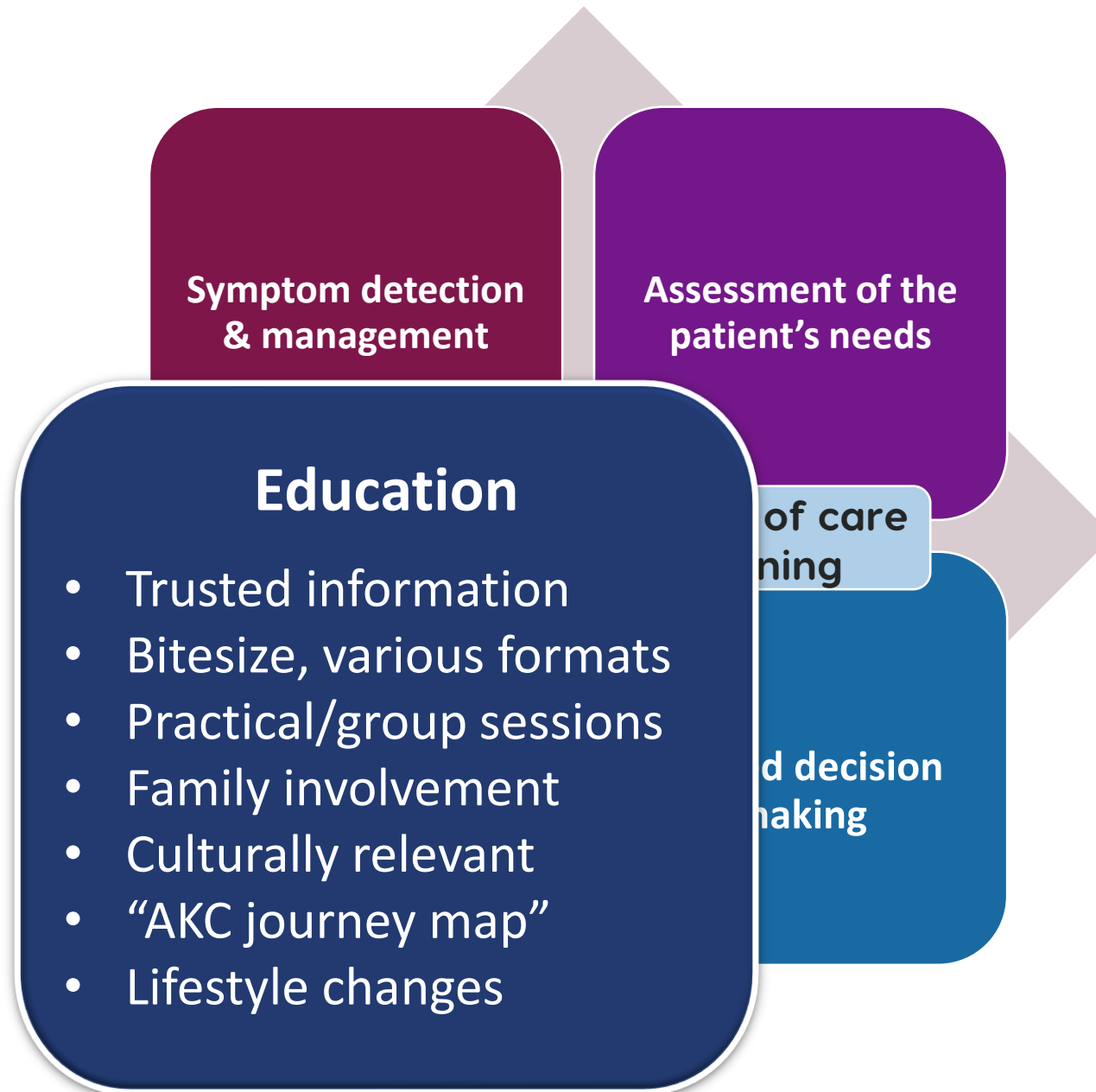
Patient
education

Shared decision
making

Patient insights webinar

"Ideal care" themes





Patient insights webinar

"Ideal care" themes

Symptom detection & management

Assessment of patients' needs

Accessibility
Staff education

Patient education

Shared decision making

- Get to know me
- Build trust, continuity
- Simple explanations
- Address fears
- Plans A, B, C
- Meet other patients

Patient education and information day

People living with Kidney disease, pilot sites, Kidney Care UK



- **Tailor to what is most important to them**
- Explain the “big picture” – create roadmap
- Give information at the right time for them
- Explain in simple terms
- Balanced information
- Variety of formats, culturally relevant
- Charities’ information resources are highly trusted
- Signpost to more detailed information & kidney charities
- How to contact the AKC team for help



- **Top 10 things to take away from first AKC clinic**
- **Easy read formats**
- **Kidney Care UK AKC leaflet later this year**

We're here for you
Support for kidney patients and their families

Kidney Care UK

Get in touch to see how we can support you

Call free on
0808 801 00 00
(Monday to Friday, 9am - 5pm)

support@kidneycareuk.org | www.kidneycareuk.org

At Kidney Care UK we understand the challenges of living with kidney disease, and we're here for you from day one.

Our FREE patient services include:

- Financial support
- Telephone counselling
- Advice and support
- Trusted information
- Benefits support
- Fighting for better care

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Transform AKC Professionals' webinar

November 2024



What is
ideal care?

What are the
barriers to
delivering it?

What works particularly well in your service?

- AKC clinics closer to home
- Face-to-face interpreters
- Cultural health improvement officer
- Group patient education sessions
- Home dialysis roadshows
- One-stop transplant workup
- Geriatric assessment for frail patients
- Young adults group
- Local peer support programme

Unmet needs staff most concerned about



Geographical inequities

Timeliness of vascular access

Transplant workup

Peer support

Psychosocial

Living donation

No multidisciplinary AKC clinic

Frailty assessment

Late referrals

Patient education

Physio / OT

Conservative management

Shared decision making

Ideal care - service design & delivery

Full MDT AKC available across all clinic sites

(nurse, doctor, dietician, PT, OT,
psychologist +/- young adult / geriatric
assessment)

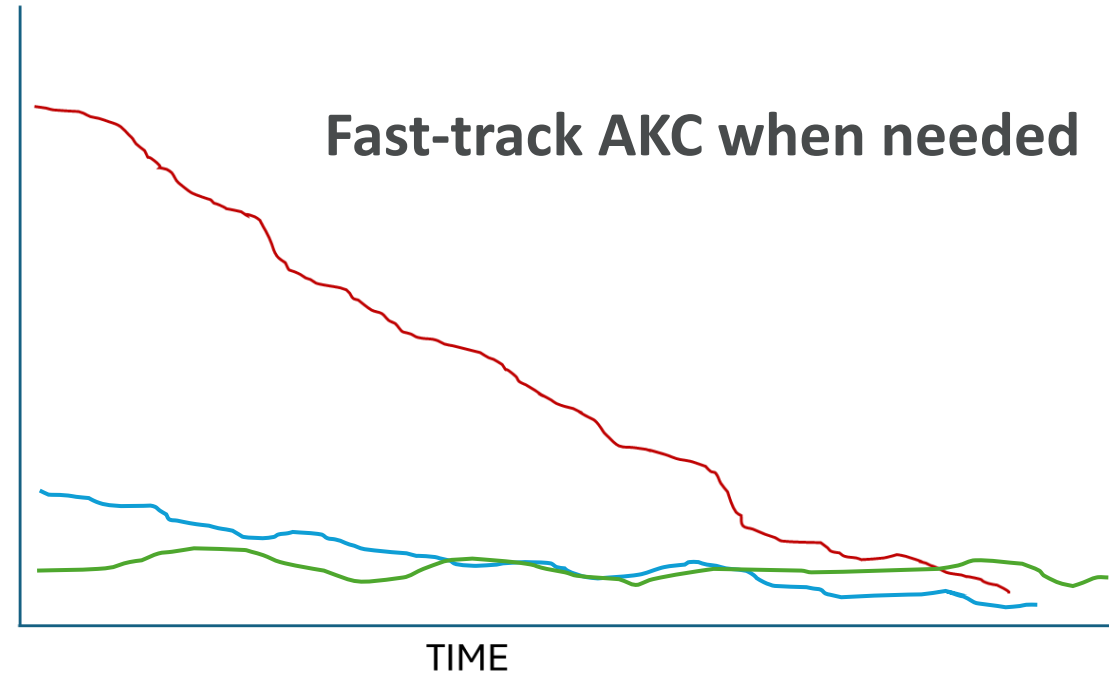
Target
resources to
those in
most need

Continuity
of care
Experienced
team

Early
promotion
of living
donor
transplant

KIDNEY FUNCTION

Fast-track AKC when needed



Ideal care - service design & delivery

Full MDT AKC available across all clinic sites

(nurse, doctor, dietician, PT, OT,
psychologist +/- young adult / geriatric
assessment)

Target
resources to
those in
most need

Continuity
of care
Experienced
team

Early
promotion
of living
donor
transplant

Barriers to providing it

- Lack of space / funding / staff
- Lack of IT to support service improvements
- Socioeconomic & health literacy challenges
- Transplant workup /surgical bottlenecks

Ideal care – shared decision making (SDM)

Videos, website, leaflets,
decision aids, group sessions, see
equipment, meet other patients

Allow 12-18
months

Highly trained staff make holistic assessment

Personalise according to the patient, according to
their needs, priorities & culture

Ideal care – shared decision making (SDM)

Honest
discussion of all
options

Discuss
psychosocial /
financial issues

Signpost to peer
support
(local / national)

Videos, website, leaflets,
decision aids, group sessions, see
equipment, meet other patients

Allow 12-18
months

Highly trained staff make holistic assessment

Personalise according to the patient, according to
their needs, priorities & culture

Ideal care – shared decision making (SDM)

Barriers to providing it

- Late referral for shared decision making and transplant workup
- Lack of accessible educational formats
- Lack of staff time & training
- Language & cultural barriers

Honest
discussion of
all options

Discuss
psychosocial /
financial issues

Signpost to
peer support
(local /
national)

Videos, website, leaflets,
decision aids, group sessions,
see equipment, meet other
patients

Allow 12-18
months

Highly trained staff make holistic assessment
Personalise according to the patient, according to
their needs, priorities & culture



Literature review Interventions to improve AKC

Review article



- Risk prediction models, e.g. KFRE
- Communication techniques for shared decision making
- Patient decision aids
- Renal geriatric assessment in practice
- Interventions for ethnic minorities

- Apps to improve self-management
- ePROMS for symptoms & patient activation
- Psychosocial support for care-givers
- Mental health symptom screening tools
- Exercise programmes
- Pharmacy interventions

Pilot renal units have started QI projects to test improvements in care



Pilot renal units

Kilmarnock - frailty

Bradford – patient education events

Nottingham – symptoms management

Stevenage – pre-emptive transplant

Royal Free, London - health literacy

The AKC challenge



- Recognise the needs of our patients and carers
- Resources and skills to deliver all aspects of ideal care
- **Tailoring care to the individual**
 - Age
 - Location
 - Individual needs & experiences
 - Speed of deterioration in kidney function
 - Other health problems
 - Culture



People living with kidney disease “a conversation”



Helen Woolley



Edmund Clotey



Patricia Gooden



Next steps

- Pilot sites continue projects, ongoing patient involvement
- Develop AKC toolkit
- Collaboration with Kidney Care UK – new AKC patient info leaflet
- Transform AKC Year 1 report
- Webinar Autumn 2025 to share project updates and gather ideas from AKC community of practice
- AKC Summit May 2026
- **Pdfs of slides and workshop information will be emailed on completion of feedback**



For more information, email
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