#LearningFrom…
Kidney Services Improving at Scale
Online learning session 1:

Patients and Professionals working together to improve kidney care

Practical examples from four leading quality improvement programmes

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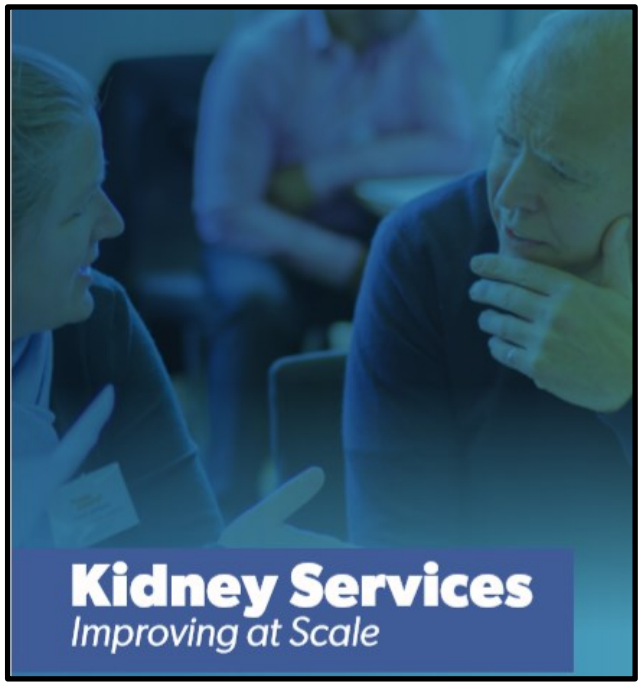
Kidney Patient INVOLVEMENT NETWORK

KQuIP



The Kidney services: Improving at Scale report shares the experiences of those involved in four scaled up quality improvement programmes.

It provides information for those planning to take a locally developed and proven intervention to the next step of spreading to other locations by specifically considering five themes.

This webinar covers the Patient Involvement and experience theme (Chapter 9).

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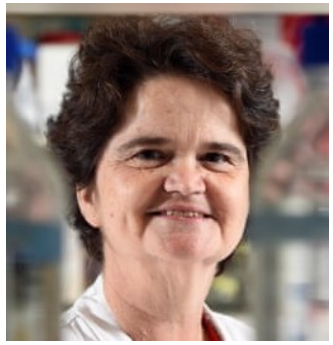
The Panel

Martin Wilkie



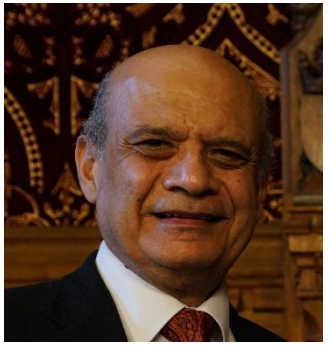
Claire Corps

Amjid Ali

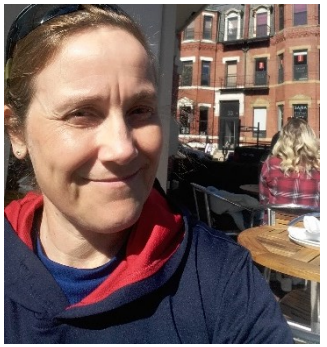
Nick Selby

Tracey Rose

Andy Henwood



Kirit Modi



Sonia Lee

Dela Idowu

[Click here for further information on the panellists]

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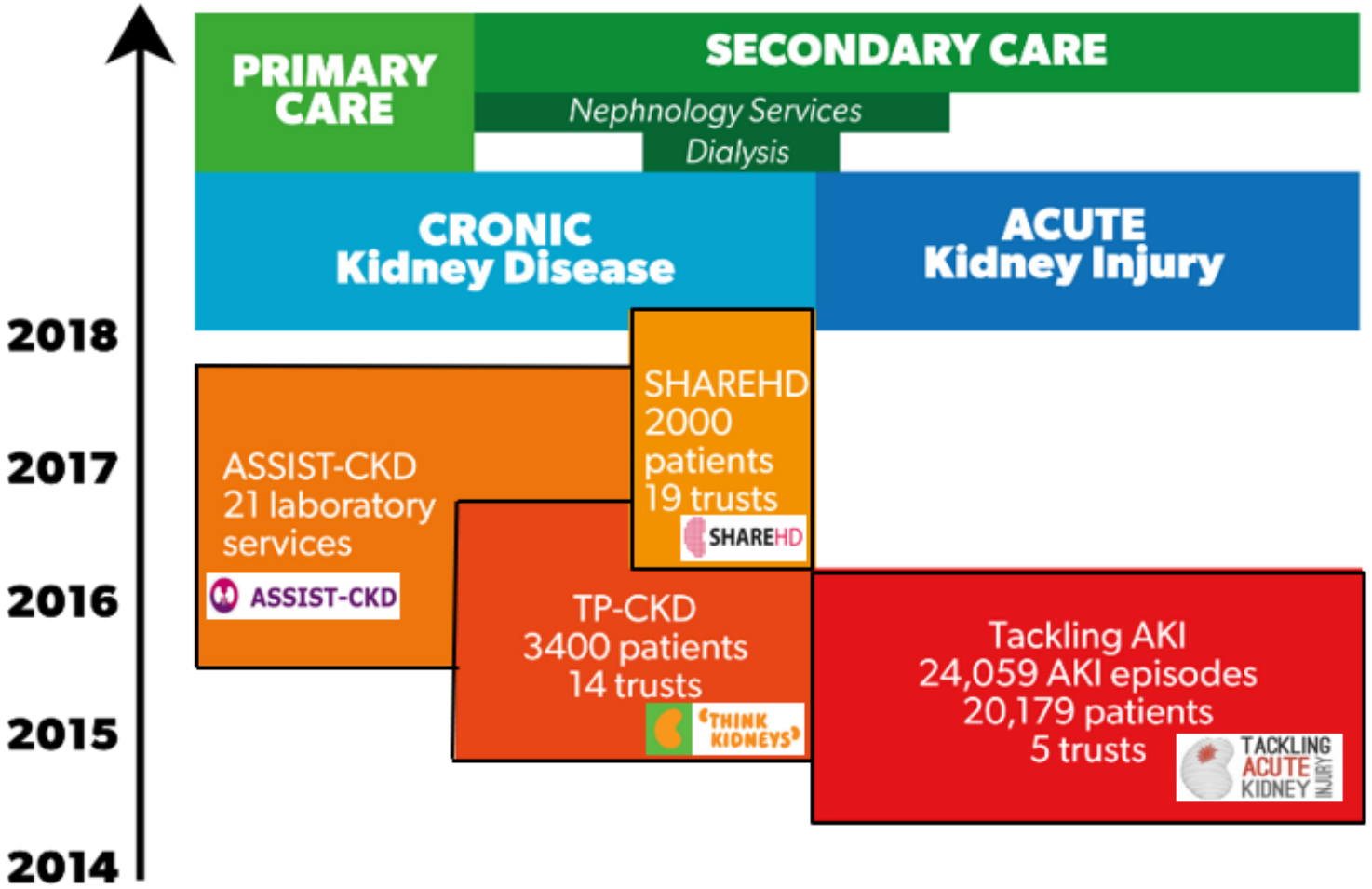
The scaling up programmes



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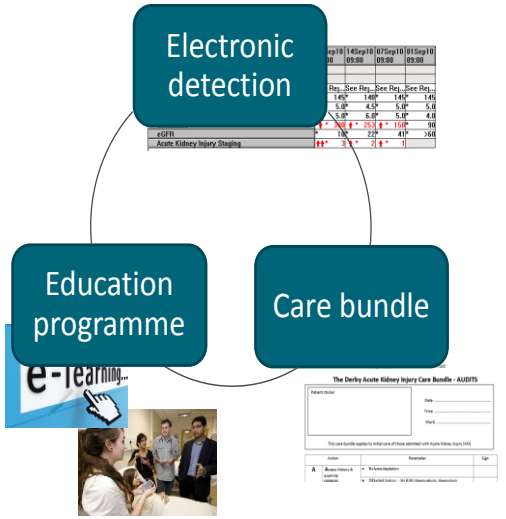
Tackling AKI

* To examine whether a hospital based intervention was able to improve AKI recognition and care delivery

* The intervention had three components
  * an electronic detection and alerting system
  * a care bundle covering assessment, investigation and basic management
  * an educational programme to raise awareness and knowledge of AKI in healthcare



* First tested at Derby Royal Infirmary

* Patient involvement via local patient groups and involvement within hospital teams

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ASSIST-CKD

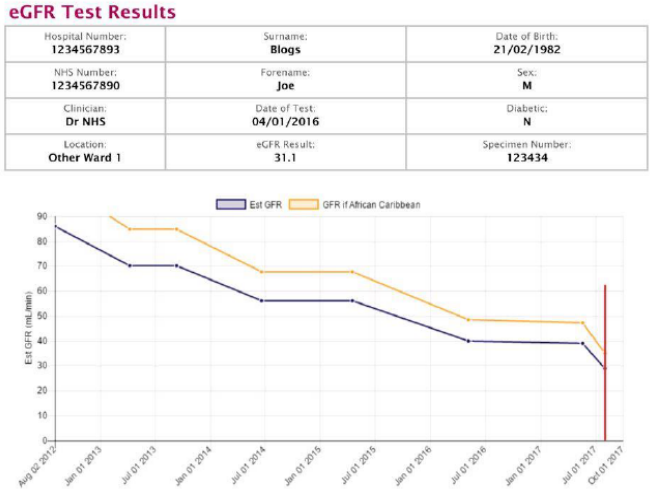
'A programme to **S**pread eGFR graph **S**urveillance for the early **I**dentification, **S**upport and **T**reatment of people with progressive **C**hronic **K**idney **D**isease'

* Objective was to reduce late presentation for renal replacement therapy

* The intervention trained lab staff to
  * read eGFR graphs
  * identify those at high risk of deteriorating kidney function
  * flag details to GPs for action

* First developed at Heart of England NHS FT

* Recruited at start a patient involvement group and patient lead to support the programme



eGFR Test Results

Hospital Number: 1234567893	Surname: Blogs	Date of Birth: 21/02/1982
NHS Number: 1234567890	Forename: Joe	Sex: M
Clinician: Dr NHS	Date of Test: 04/01/2016	Diabetic: N
Location: Other Ward 1	eGFR Result: 31.1	Specimen Number: 123434

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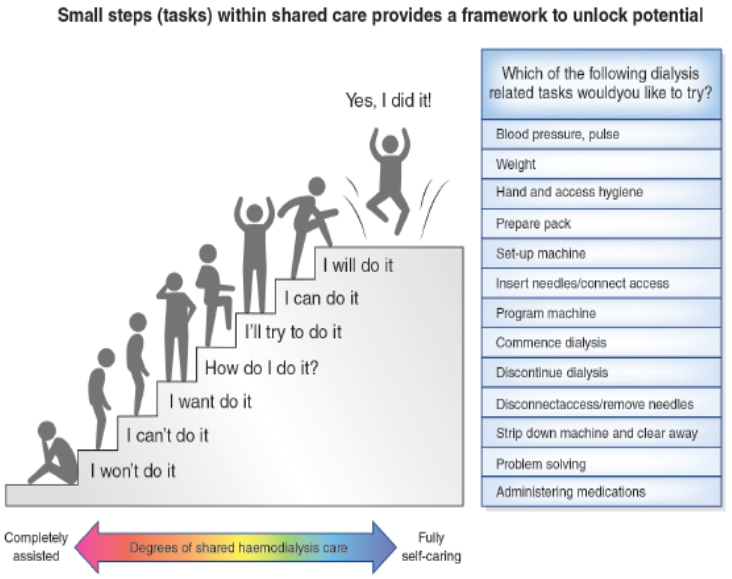
SHAREHD

* To routinely offer patients the opportunity to participate in component tasks related to their haemodialysis treatment

* The intervention
  * offers support and training geared towards personal goals
  * progress documented using a competency record
  * underpinned by bespoke educational materials

* Developed and tested in Yorkshire and Humber

* Recruited a Patient lead and Patient Advisory Group
  Each team was asked to include a patient advocates who met together as a Patient forum at the learning events



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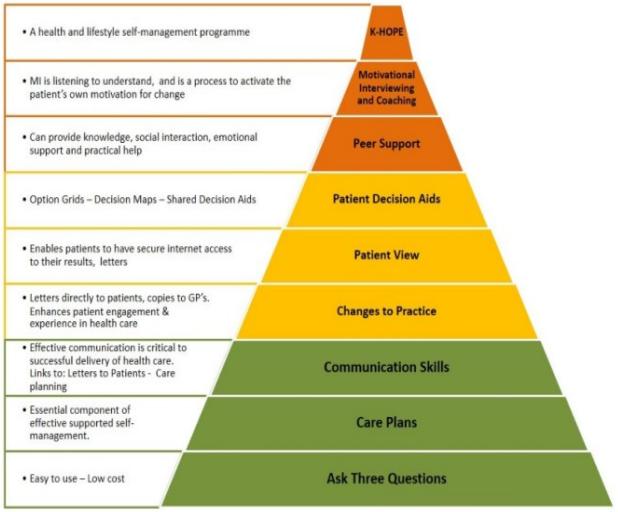
TP-CKD

* To support people to build skills knowledge and confidence to self manage their health

* The intervention
  * developed tools to gather patient information on outcomes that mattered to them
  * tested if this tool can be routinely collected within the clinical setting and returned to the UK Renal Registry
  * Developed intervention toolkit to improve patient knowledge skills and confidence

Programme board and all groups were co-chaired with patients – strove for a 50/50 patient representation and all teams to include patient partners



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Key report themes

* **The improvement idea:** what is the intervention and how can it be implemented ?
* **Change Management:** what is the theory of change and the appropriate QI mechanisms ?
* **Evaluators:** what are the processes to evaluate progress and enable learning. ?
* **Service Users and Co-production:** how to involve and understand the impact on patients and front line staff ?
* **Delivery Team:** how to build a learning environment that delivers improvement to time, cost and quality ?

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Patient Involvement and experience
Key learning and examples

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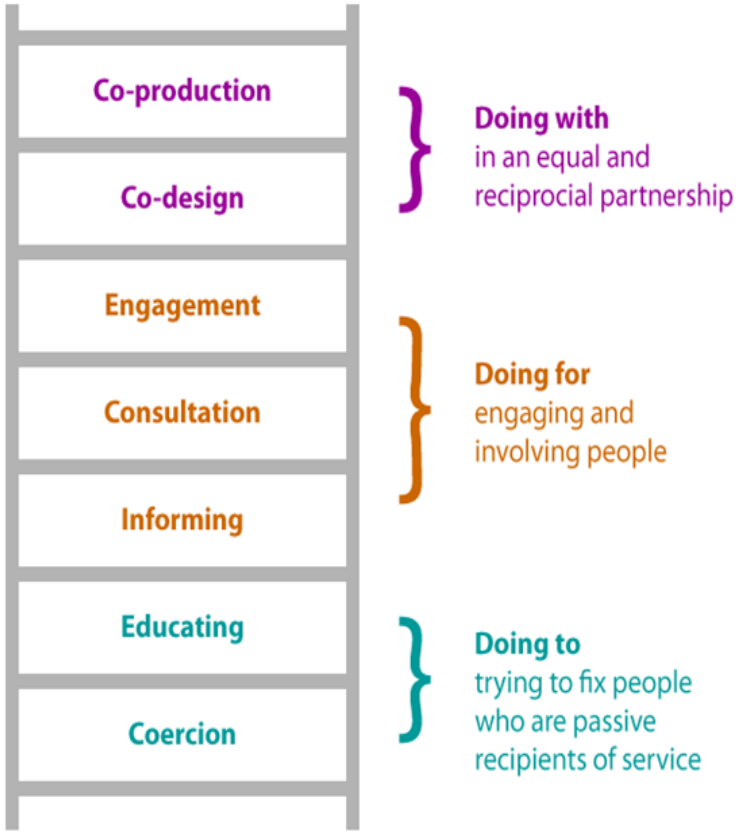
Why involve patients ?



The co-production ladder

Ref : https://www.thinklocalactpersonal.org.uk/

Not involving patients in developing service or quality improvements that are aimed at improving outcomes for them runs the danger of being misdirected or meaningless.

Doing nothing or maintaining the status quo is not good enough we have to be proactive to change. But what does good look like?

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Setup

Aim to involve more than one patient representative

* avoid relying on a lone patient representative.
* where appropriate aim for an equal ratio of patients to healthcare professionals

Involve patients early

* involve patients before there is a project
* get patient ideas for what to improve
* reflect the patient voice throughout the scoping, development, funding/ contracting stages

TP- CKD – co-chaired work streams and equal board representation. But there was no patient involvement in contract negotiations.

SHAREHD – just 1 patient involved during the development stage but patient level forum was set up using WhatsApp that enabled patient champions to engage within local trusts.

Making it Work

Describe the patient role clearly

* prepare a written brief for the patient roles
* give a personal briefing on the remit and expectations at the start

Aim to be genuinely representative

* reflect the demographic of the recipients of the intervention among the patient partners.

ASSIST–CKD : Formal recruitment of patient lead. Started with 10 patients anticipating that some would leave the project.

SHAREHD : worked with patient champions to understand expectations, developed engagement descriptions and a simple induction programme.

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Making it Work

Develop review mechanisms

* build mechanisms with patient partners for continuous reflection and review of experiences

Match involvement to motivation

* understand why patients get involved and allocate activities that relate to them
* patients don't have to be involved from start to finish
* specific actions may work better for some
* be prepared to be flexible

ASSIST-CKD: matched experience and motivations from the recruited group to the roles as they emerged eg Business Case development

Tackling AKI: Clinician with experience of AKI spoke at education sessions bridging the gap between patients and staff

Expectation Management

Be clear about expenses and remuneration

* ensure the policy is widely available
* budget accordingly
* policies are available https://www.england.nhs.uk/wp-content/uploads/2017/08/patient-and-public-voice-partners-policy-july-2017.pdf

Consider accessibility of meetings

* timing and format
* venue and accessibility
* teleconference options

SHAREHD : agreed remuneration with Patient lead upfront and followed INVOLVE guidelines

Asif: unable to attend advisory groups as worked and could not get the time away to call in to teleconference (SHAREHD)

Lisa: unable to call into teleconference as did not have funds to pay for the call cost (SHAREHD)

Working together

Develop peer support

* Establish peer support mechanisms for patients involved in the improvement work.

Foster co-production more broadly

* Ensure professionals understand the importance of user involvement
* support them to plan and implement this way of working throughout all their interactions
* Foster ongoing co-production not just when in 'improvement project' mode.

SHAREHD: Use of social media and WhatsApp groups. A patient forum was held at each event feeding back to the rest of the attendees.

TP-CKD: set expectations with each trust that having a patient participant was essential.

Working together

Consider the longer term patient role

* encourage patient advocacy
* maintain a level of communication and links with involved patients beyond a specific project
* sign post to organisations such as the Kidney Patient Involvement Network.

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Summary

- Involve more than one patient representative
- Involve patients early
- Describe the patient role clearly
- Be genuinely representative
- Develop review mechanisms
- Match involvement to motivation
- Be clear about expenses and remuneration
- Consider accessibility of meetings
- Develop peer support
- Foster patient co-production more broadly
- Consider the longer term patient role

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Good Practices and Signposts

Visit the Kidney Patient Involvement Network for:

* Examples of good practice and case studies
* Resources, tool-kits, example terms of reference and protocols
* Support and training for kidney patient and family involvement

BAME Toolkit:

The BAME Toolkit is a useful resource to help you address issues of inclusion and equality with respect to BAME communities.

Date for your diary:

Second Annual American Association of Kidney Patients (AAKP) George Washington University Innovation Summit on July 16th and 17th

Virtual and free of charge – register here

Key organisations:

* Kidney Care UK
* NIHR INVOLVE
* National BAME Transplant Alliance
* National Voices
* Kidney Research UK
* National Kidney Federation
* Polycystic Kidney Disease Charity

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