

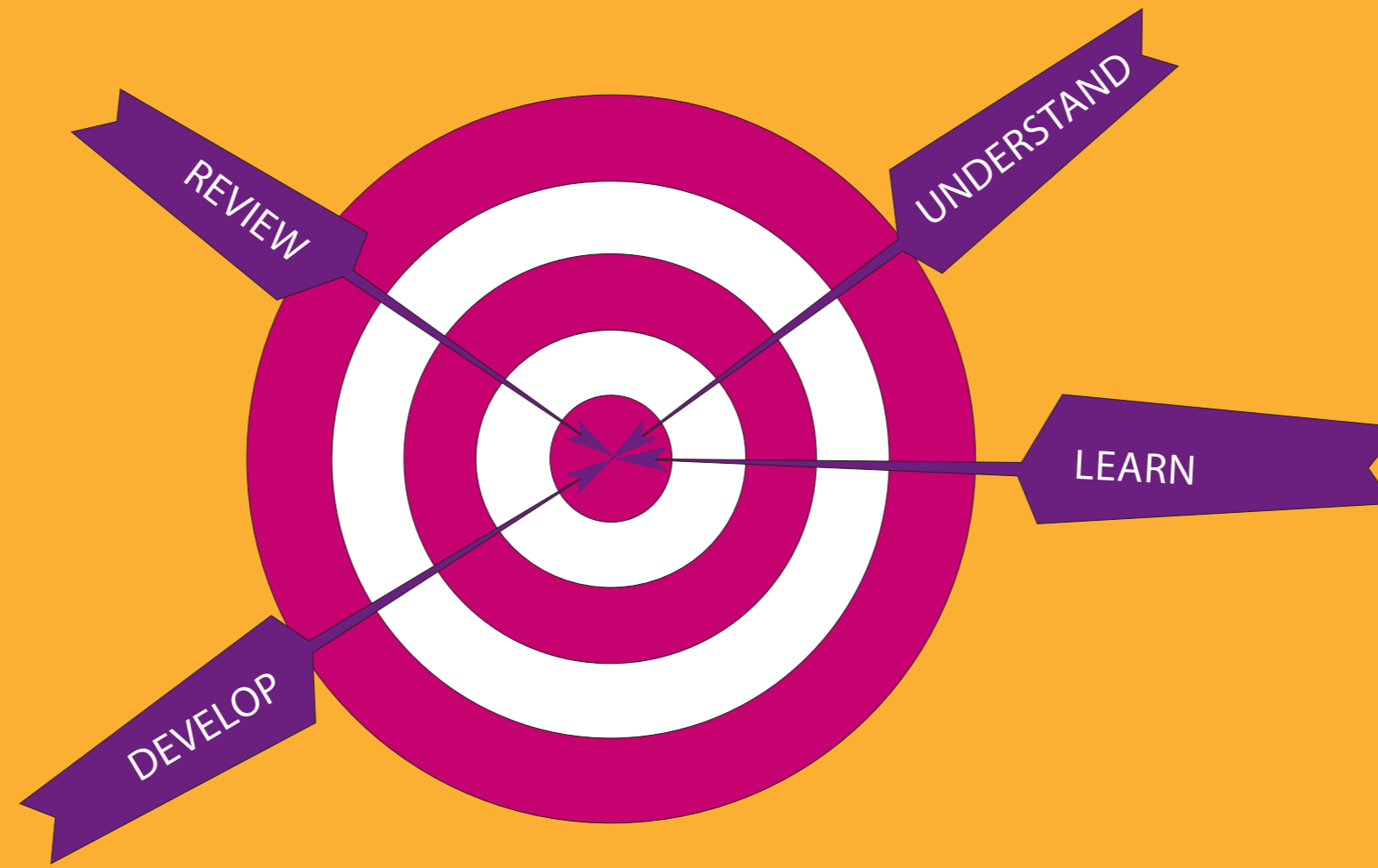
Putting patients and families at the **HEART** of our kidney research

Currently there is no cure for kidney disease...

Kidney Research UK is the leading national charity funding research into prevention, better treatments and cures for kidney disease.

We believe that research into kidney disease is only worthwhile if it makes a real difference to people and families. We want to increase our engagement with patients and their families and build on our success and key learnings to date.

OUR AIMS



- To **understand** how we could involve patients in clinical trials more effectively
- To **learn** more about how best to engage with patients
- To **review** the quality of our current engagement with patients
- To **develop** a clear strategy and an integrated approach to patient engagement

THE NEED

- The number of patients **engaging** with our research programme was relatively low
- There is a **perception** of patients being treated as numbers not people in research projects
- Evidence suggests that patient **involvement is key** for research success



WHAT WE DID

Volunteer research 'champions' visited local renal units and out-patient clinics...

in Mid-Wales and Shropshire to discuss kidney research and involvement in research with dialysis patients and their families.

Patients were approached with consent from the renal unit manager and unit sister or matron and discussions were on a 1-2-1 basis.

OUR LEARNINGS

- We gained a greater understanding of how patients **wanted to be involved** in research
- We established the need for a **'toolkit' approach** – a questionnaire to capture people's opinions and information on the impact of research into kidney diseases and their current treatments
- We discovered that **relationship building** is key – as well as developing support for patients and their families
- We found that peer to peer **education** is vital
- We need to improve the **accessibility** of tools and information

THE OUTCOMES

- We have made information and resources **more accessible** and **more engaging** for patients & carers
- We have adopted a **proactive approach** to patient engagement - involving patients in a range of activity, research engagement days, media work, and health information resources
- We have **broadened our reach** to new patients and their families

**MORE ACCESSIBLE
MORE ENGAGING
PROACTIVE APPROACH
BROADEN OUR REACH**

To find out more about our work with patients, or how you can get involved, talk to the team, or visit:

www.kidneyresearchuk.org/get-involved

