



Llywodraeth Cymru
Welsh Government

POLICY AND STRATEGY, DOCUMENT

Quality statement for kidney disease

The quality statement describes what good quality services for kidney disease should look like.

First published: 30 November 2022

Last updated: 30 November 2022

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Quality statement

Kidney disease affects approximately 10% of the global population with diabetes and hypertension being amongst the commonest causes. The increasing prevalence of such conditions in our communities suggests we are likely to see more Welsh people with kidney disease requiring therapy, including those with mild disease in the community through to those requiring specialist care with dialysis and transplantation.

Kidney Replacement Therapy (KRT) such as dialysis is provided to around 1,400 adult Welsh residents and around 100 kidney transplants are undertaken each year. There are also almost 1,800 Welsh patients living with a functioning kidney transplant, who require ongoing clinical review, psychosocial support and immunosuppressive drug treatments. All forecasts consistently demonstrate that the need for these services for adults will grow by 4-5% year on year.

The number of children reaching end stage kidney disease per annum is around 2 per million of the total population. In Wales this corresponds to approximately 6 new cases per year. There are approximately 50 children on Kidney Replacement Therapy (KRT) in Wales at any one time, many with a kidney transplant. The need to ensure a smooth transition from children's to adult health services, as outlined in [Transition and handover from children's to adult health services](#) guidance, is recognised as an integral element of the pathway.

Building on the work of the Renal Delivery Plan (2016-2020) the next five year phase of service development for people with kidney disease must take advantage of the widespread consensus on priority areas, bring programmes to fruition, and maintain the national leadership, local engagement and collaboration with third sector that has been achieved. This will ensure that there is a long-term and consistent approach to improving outcomes as envisaged in the Wellbeing of Future Generations Act and demonstrated by international

experience.

The introduction of quality statements were signalled in ‘**A Healthier Wales**’ and has been described in the **National Clinical Framework** as the next level of national planning for specific clinical services. Quality statements form part of the enhanced focus on quality and will be integral to the future planning and accountability arrangements for the NHS in Wales.

Kidney services in Wales were significantly impacted by the COVID-19 pandemic, and the learning from the need to adapt to the challenges has influenced the approach of this Quality Statement. As a consequence, it includes the immediate, short-term focus on recovery and also consideration of the medium and longer-term potential for transformation.

There is a need to ensure that equity of access is provided for those people who have faced inequality, such as, for example, **ethnic minority** communities and the LGBTQ+ communities and pathways will need incorporate more flexibility to deliver this. The Welsh Government’s “**More than just words**” plan to strengthen Welsh language in health and care services through the ‘active offer’ principle should become an integral part of service provision. Service providers should build on current best practice and plan, commission and provide care based on this principle.

The vision is to develop a Kidney Integrated Care Pathway (KICP) to provide the overarching framework for the delivery of kidney care from prevention to supporting patients to decide on the form of kidney replacement therapy that is right for them. The KICP will aim to drive system-wide improvement through a reduction in unwarranted variation of care and improved patient outcomes.

This approach aligns with the National Clinical Framework which places specific emphasis on the development of national clinical pathways and the **Quality Safety Framework** which emphasises the importance of systemic local use of

the quality assurance cycle.

It also enables a focus on cross-working with other groups to address areas such as prevention, rehabilitation, organ donation and transplantation, care for those who are critically ill or at end of life as well as collaboration with other conditions such as heart conditions, stroke, diabetes and vascular.

Health boards are responsible for the delivery of kidney services in line with professional standards and the quality attributes set out below. Health boards will be directed, supported and enabled to deliver improved services. The Welsh Kidney Network (WKN) will set out a rolling, three-year implementation plan that identifies and prioritises developments based on the quality attributes described below. Detailed service specifications will also be developed to support the commissioning and accountability arrangements including key metrics for delivering high quality and sustainable kidney services that meet the needs of the population. These will be set out in Annex A as they become available.

Quality attributes of services for people with kidney disease in Wales

Equitable

- National approach led by the Welsh Kidney Network to deliver service improvement through its network board in conjunction with the NHS Executive.
- A Kidney Integrated Care Pathway will ensure transparency, support equity of access, consistency in standards of care and address unwarranted variation.
- Services for people with kidney disease will be measured and held accountable using metrics, clinical audit, PROMs and peer review that reflect

the quality of patient care and its outcomes.

- A 'kidney transplant first' approach, before a patient needs to consider dialysis is adopted. This will include early identification of all potential patients for transplantation, particularly pre-emptive transplantation and potential living kidney donors.
- Provision of as much treatment and support as possible close to or in the patient's home, with home dialysis being a first choice if kidney transplant is not possible.
- Kidney care workforce is supported and developed, to address staff retention and ensure it is sustainable, equitably distributed, grown to meet increased demand with focus on key areas such as kidney health and wellbeing support and specialist nursing.

Safe

- A system-level focus on transforming pathways to further build in resilience by adopting the learning that achieved throughout the pandemic.
- Evidenced patient safety improvement programmes are embedded utilising the all Wales incident reporting system to identify themes and share collective learning points.

Effective

- Patients at risk of kidney disease or in the early stage of diagnosis are actively supported and involved in the management of their disease, including lifestyle modification support.
- Children and Young people should be provided with care appropriate to their age and needs with the transition to adult services appropriately supported to ensure a smooth transition of care.
- A culture where all patient's needs, not just kidney care are understood ensuring the right support is provided at the right time, utilising a whole

system approach including other specialties such as diabetes and services such a peer support provided by third sector.

Efficient

- A national approach to the kidney informatics system (VitalData) to enable greater integration of care and provide relevant, high quality, standardised data to guide service development and inform commissioning needs.
- Building on new ways of working by using technology to free up more time to care such as the electronic prescribing and medicines administration (EPMA) programme that enables the safe and efficient management and administration of medication.

Person Centred

- Patients are supported to self-manage wherever possible using digital communications to facilitate and coproduced care plans.
- Patients are actively involved in on-going management and decision making processes regarding treatment of their kidney disease. Ensuring that patients are supported to understand the likely trajectory of their disease, including a reasonable estimate of prognosis including information and support about Advanced Care Plans to enable them to record how they would wish to be cared for at the end of life no matter which treatment option they choose.
- Patients are well-prepared for dialysis (if transplantation not clinically indicated), including commencing on preferred type and place of dialysis, with a permanent vascular access in place.
- Collaborative approach to person-centred care is culturally embedded and supported by a common approach to diagnosis, treatment and care provided within the community where appropriate.
- PROMS and PREMs are used to better understand care and service needs to ensure people affected by kidney disease achieve the outcomes that

matter to them.

- Outcomes from the research studies undertaken in Wales and globally are utilised to inform how we model delivery of care and patient education.

Timely

- Validated mechanisms for identifying people at risk of developing kidney disease and those at the early stages of disease will be used to support primary care to ensure timely referral to secondary care.
- Opportunities to implement new medications proven to reduce the progression of kidney disease and associated cardiovascular disease are explored and implemented.

Annex A: Service specifications

The WKN will develop service specifications for kidney disease pathways to inform accountability discussions and commissioning decisions. These will be added as they become available.

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