Milestone 12 - Consensus Report for 4-Factor LCA Ready for Implementation in Dashboard

Work Package 5, Milestone 12

Authors: Aycan Yasar and Ingeborg Steinbach

List of Contributors

Contributors to this Milestone are outlined in Table 1.

Name	Organisation	Contribution
Aycan Yasar	CSH	Co-Author
Ingeborg Steinbach	CSH	Co-Author

UK Research
and Innovation

Co-funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of HADEA. Neither the European Union nor the granting authority can be held responsible for them. Privacy policy.

Technical references

Project Acronym	KitNewCare
Project Title	Developing a framework/model to environmentally sustainable and climate neutral health and care systems using the kidney care pathway
Project Coordinator	Brett Duane Trinity College Dublin (TCD) brett.duane@dental.tcd.ie
Project Duration	January 2024 – December 2027 (48 months)

Milestone No.	12
*Dissemination level**	PU
Work Package	WP 5
Lead beneficiary	Centre for Sustainable Healthcare (CSH)
Contributing beneficiary/ies	CSH, TCD
Due date of deliverable	31 March 2025
Actual submission date	26 March 2025

PU = Public

PP = Restricted to other programme participants (including the Commission Services)

RE = Restricted to a group specified by the consortium (including the Commission Services)

CO = Confidential, only for members of the consortium (including the Commission Services)

v	Date	Beneficiary	Author
1.0	20/02/2025	CSH	Aycan Yasar and Ingeborg Steinbach

1. Table of Contents

2. Introduction

2.1. Milestone Purpose and Scope

KitNewCare's Milestone 12, *4-factor LCA ready for implementation in dashboard* takes the form of a consensus report on the KitNewCare.eu website. It summarises the results of four workshops and a follow-up activity held by the Work Package 5 team.

2.2. Target Audience

The target audience for this milestone are:

1. Stakeholders in the KitNewCare (KNC) project, including the clinical pilot sites
2. Healthcare professionals and healthcare managers
3. European Commission

2.3. Background

The KNC project, co-funded by Horizon Europe's Health Program and UKRI, aims to develop a model for sustainable healthcare, with kidney care as our focus. It will address the triple challenge of improving knowledge amongst healthcare professionals and organisations and improving the availability of sustainable solutions, like process optimisations and technical innovations, their implementation and spread.

To support the implementation of sustainable solutions, Work Package 5 will develop an online benchmarking tool with a dashboard serving as its user interface. This tool will measure and monitor four key impact areas: environmental, social, and financial impacts, as well as health outcomes. It will assess the performance of kidney care centres across different treatment options, including peritoneal dialysis (PD), in-centre haemodialysis (ICHD), home haemodialysis (HHD), transplantation, and conservative therapy. By monitoring these metrics over time, the benchmarking tool will help centres identify performance trends and improvement opportunities in all four impact areas.

The tool will help healthcare professionals and managers to make sustainable choices. It will provide policy makers with information to progress with the sustainability agenda, developing policies which will accelerate the transformation to sustainable healthcare on the ground.

The tool will have three user interfaces:

1) An interface only accessible by kidney centres themselves which shows their centre's own impacts over time along with the impact of their treatment options and sustainable changes identified in Work Packages 3 and 4 and benchmark their centre against national and European averages.

2) An interface with aggregated country-level information that benchmarks them against European averages.

3) An interface with aggregated European Union level information that shows the impact of kidney centres across the European Union.

The development of the benchmarking tool should take into account three main considerations:

1) The information collected and displayed by the tool should support clinical and operational decision making.
2) The need to balance accuracy and ease of use.
3) Having long term viability, which would have an influence on the variables and databases chosen.

2.4. Objective

The objective of this milestone is to reach a consensus with the clinical sites and the stakeholders of the benchmarking group on the impact indicators and metrics the benchmarking tool will use to measure and monitor the four impacts.

3. Methodology

In support of the decision-making process, several steps were taken:

- Site visits
- Workshop with KNC's four clinical pilot sites
- Two workshops with the benchmarking group stakeholders
- Workshop with the clinical sites and benchmarking group stakeholders present at the Annual General Meeting (AGM) in Madrid

3.1. Site Visits

During visits to the clinical pilot sites in year one of the project, health outcome, social impact and cost measures currently used at the sites were identified. The structure of each country's health system was discussed to understand how this can support the embedding of the benchmarking tool. These discussions took place at the pilot sites in Utrecht, Modena, and Warsaw, but could not be facilitated in Madrid.

3.2. Workshops

3.2.1. Workshop with KNC's clinical sites

An initial workshop took place with healthcare managers and healthcare professionals across the four clinical pilot sites of KNC: Utrecht, Warsaw, Modena, and Madrid. Additional healthcare managers and healthcare professionals from Barcelona, an associate clinical site, attended. This workshop, lasting two hours, discussed all four impacts: health outcomes, social impacts, environmental impacts, and costs.

The aim of this workshop was to further understand what data within the four impact areas sites currently collect and identify indicators and metrics which would provide the right information for renal centres to improve the sustainability of their care and therefore should be considered to be included in the benchmarking tool.

A further follow-up exercise was conducted with the clinical sites to help narrow down the choice of surveys to be used for assessing Patient Reported Outcome Measures (PROMs) and social impact indicators by the benchmarking tool.

The results of the workshop fed into discussions with the benchmarking group.

3.2.2. Workshops with the benchmarking group

A benchmarking group with stakeholders across the project (see 3.3) was created to support the development of the benchmarking tool.

Two workshops, lasting 1.5 hours each, were conducted. The first workshop reviewed potential indicators and metrics for health outcomes and social impacts whilst the second workshop covered environmental impacts and costs. The aim of these workshops was to discuss and confirm indicators and metrics the benchmarking tool should collect and monitor to improve the sustainability of kidney care centres and their treatment options. Moreover, it explored potential barriers to data collection and ways how to overcome them.

3.2.3. Workshop in the project's AGM

During the project's AGM in Madrid, a workshop was held with the clinical sites and the stakeholders of the benchmarking group where different surveys for Quality of Life (QoL), PROMs, Patient experience, Staff experience and Carer experience were explored. The analysis included exploring the practicality of some of the tools and diving into the pros and cons of the surveys. The aim was to reach a consensus on the surveys which will feed into the benchmarking tool.

In summary, the workshops conducted aimed to:

- Deepen our understanding on what indicators in the four impact areas are already collected at the four clinical sites.
- Discuss and determine the indicators and metrics the benchmarking tool should measure to support healthcare professionals and healthcare managers to improve the sustainability of kidney care.
- Prioritise measures to understand the most useful options.
- Analyse approaches that can simplify and overcome potential barriers in data collection.

3.3. Stakeholders

- The first workshop was conducted with healthcare professionals and managers from the four KNC pilot sites, Utrecht, Warsaw, Modena, and Madrid along with healthcare managers and healthcare professionals from the associate site in Barcelona.
- The second and third workshops took place with the main benchmarking group which consisted of partners across the KNC consortium including two representatives from the clinical sites, the European Kidney Health Alliance (EKHA), European Renal Association (ERA), European Kidney Patient Federation (EKPF), The European Dialysis and Transplant Nurses Association/European Renal Care Association (EDTNA/ERCA), ICONS, 040, the project's health economist, the LCA team, and a couple of members from the Scientific Advisory Board.
- The workshop in Madrid was conducted with the pilot clinical sites, Utrecht, Warsaw, Modena and Madrid along with representatives from the benchmarking group which were present at the AGM.

3.4. Approach

All three workshops took a similar structure. Before the workshops, background material was sent to the groups to provide prior insight to the sessions. During the workshops, each of the impact categories were introduced during a brief presentation followed by either a breakout session or a Mentimeter exercise.

Workshop breakout sessions

- Guided discussions in breakout sessions following pre-set questions to identify indicators and metrics already collected in the four impact areas, and indicators and metrics in the four impact areas which would support improvements in sustainable kidney care and therefore should be measured, recorded, and monitored by the benchmarking tool. Potential barriers and facilitators for data collection were also explored.

Mentimeter exercises

- Mentimeter exercises engaged participants in prioritising and/or ranking of environmental impact indicators according to their usefulness in supporting decision making for more sustainable kidney care. Mentimeter was also used to rank PROMs/QoL measures with respect to their usefulness of capturing the impact of kidney care on patients.

Post workshop follow-up exercises

- For the clinical sites workshop, a follow-up Google Forms exercise focussed on understanding the clinical sites preferences concerning the discussed QoL/ PROMs, Patient Reported Experience Measures (PREMs) and staff experience measures in order to narrow down the options of measures that will feed into the benchmarking tool.

3.5. Tools and Frameworks

Different tools, measures and frameworks have been explored for each impact category during the workshops.

Health outcomes

- Health outcomes data from the ERA e.g. survival rates and transplantation rates[i]
- Process outcomes from the Getting it Right First Time programme e.g. hospitalisation rates and infection rates[ii]
- Patient Reported Outcome Measures e.g. EQ-5D-5L[iii]
- Quality of Life surveys e.g. Kidney Disease Quality of Life Short Form (KDQOL SF)[iv] Version 1.3, 36 and 12, and the Renal Dependent Quality of Life survey[v]

Social impact

- Patient experience measures such as the UK Kidney PREMs[vi] and the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) experience survey[vii]
- Local staff experience surveys from the pilot and associated pilot sites
- Existing caregiver surveys such as the Zarit[viii], Caregiver QoL[ix] and Caregiver Burden Inventory[x]
- The impact of the supply chain through the SOCA database[xi]

Environmental impact

- 16 Life Cycle Assessment (LCA) midpoint impact categories [xii]
- 3 LCA endpoint categories[xiii]
- LCA databases such as Ecoinvent [xiv]
- UN recommended frameworks for baseline comparisons, such as Sustainable Development Goals (SDGs)[xv]

Costs

- Different cost levels such as centre level, treatment pathway level and intervention level
- Resource costs
- Per patient costs such as a cost per patient for HD or PD
- Indirect costs such as loss in labour productivity

4. Results

4.1. Measures Currently Collected Across the Pilot Sites

Measures currently collected across the pilot sites as identified during the site visits and the workshop with the clinical sites are summarised.

4.1.1. Health Outcomes

4.1.1.1. Health outcomes

The countries of some of KNC's clinical sites have national or regional renal registries which already collect the sites' health outcomes. While some sites such as the Netherlands and some of the regions in Spain submit centre level data which is sent to the ERA, for other sites such as Poland and some areas of Italy, aggregated data at country level is submitted. From the site visits and workshop with the clinical sites, it was identified that most of the sites have data readily available for patient survival rates and transplant rates. Detailed health outcomes on End Stage Kidney Disease (ESKD) including incidence, prevalence and transplant rates are not collected at every site.

4.1.1.2. Process outcomes

The process outcome measures widely collected amongst the sites are hospitalisation and infection rates, and treatment modalities, including home HD and PD rates, are tracked. While some sites have data on emergency hospitalisation, others do not. Most sites also have vascular access rates. Amputation rates are not routinely collected, but some sites can provide this information when needed.

4.1.1.3. Patient-reported outcomes

Only one of the sites currently collect PROMs. PROMs/ QoL measures are not routinely collected for the other sites. However, during clinical trials, some of the existing surveys, like the KDQOL SF 36 are used. Although not in clinical practice, there is an increasing focus seen on this.

4.1.2. Social impact

For the social impact category, patient, staff and caregiver experience have been explored as impacts that could be displayed on the tool. Currently, patient and caregiver experience are not collected at the pilot sites. One of the sites goes through a few mandatory questions about the patient's social situation and who they live with at the beginning of admissions, to understand if they need assistance after surgery, and to assess their mental health to see if medication is needed. One of the sites are already collecting staff satisfaction as this is seen as important for them. The other sites do not routinely collect any staff social impact data. There are instances where staff surveys are conducted, for example when there is a process change, to capture the thoughts and satisfaction concerning the change. Other times, there is data collected for audit purposes which occurs every 3-4 years. Some of the sites confirmed that there are some local surveys that exist, but they are not used.

4.1.3. Healthcare systems and costs

At each site the healthcare system is different. While some have an insurance-based healthcare system others have a public system or a regional based healthcare model. For sites that operate on an insurance-based health system, insurance companies have hospital cost data available. For some of the sites, granular data is lacking. For example, while some elements like healthcare utilisation and direct costs are tracked, the necessary infrastructure to collect comprehensive cost data on energy consumption, waste production, and caregiver costs is deficient. The centres have costs recorded for the treatment path, where the costs take into account multiple activities within the treatment but does not contain a breakdown of each element.

4.2. Measures Considered for the Benchmarking Tool

4.2.1. Health Outcomes

Clinical sites workshop

In the workshop with the clinical sites, there was a mention of different treatment modalities, such as HD and transplantation, having distinct outcomes and it therefore being important to prioritise different outcome measures based on the specific treatment pathway. It would also be good to capture mental and social health of patients along with general physical outcomes.

Benchmarking group workshop

During the workshop with the main benchmarking group, there was a general agreement that health outcome data collected by the ERA is important and that it would be good for the benchmarking tool to align with this. The most important measures to include seemed to be survival rates for each treatment modality followed by prevalence and transplantation rates. Additional process outcomes that were seen as useful to include in the tool were hospitalisation rates and infection rates as these are good indicators for quality of care.

The benchmarking group had mixed views on QoL and PROMs. Some believed that it would be good to have a QoL measure that is general and validated, such as the EQ-5D-5L, which can also be used for patients with other diseases. However, others believed that if we want to measure QoL in kidney patients, KDQOL is more specific. There was a shared agreement that if the KDQOL is used, a shorter version should be used, such as the KDQOL SF 36 rather than the KDQOL SF 1.3. There were mentions of Quality Adjusted Life Years (QALYs), Disability Adjusted Life Years (DALYs), and emotional measures being useful additions that could potentially be included in the tool.

Follow-up exercise

For the follow up Google Forms exercise with the clinical sites, the options presented for PROMs/ QoL were the EQ-5D-5L and the KDQOL 36 with an additional option of “other” given to provide a further opportunity for mentioning any other surveys. While there were responses recorded from all four sites, the results showed an equal split with no consensus on the PROMs/ QoL amongst the group.

Workshop during the AGM

As there was no consensus on which PROMs/QOL measure to use, a further discussion was facilitated during the workshop at the AGM in Madrid. A clear preference for the KDQOL 12 emerged as the measure is both validated for kidney patients and also easy to implement. KDQOL 12 is also the survey that one of the pilot sites regularly uses and finds useful. The EQ-5D-5L was discussed in light of it being validated in many languages, however the scoring complexities were raised as a barrier. There were comments on taking into account simplicity versus specificity of the surveys and making sure the survey chosen meets the objectives of the project and the benchmarking tool.

4.2.2. Social Impacts

Clinical sites workshop

There were mixed views on social impacts amongst the clinical sites. One of the sites is already taking actions to maintain good staff experience including conducting staff satisfaction surveys. Other sites are not regularly taking staff experience into account and so raised the importance of introducing this. There was a strong view of staff being equally important as patients. In order to provide good care to patients, staff must be happy and satisfied with their jobs.

Another view focused on caregivers**.** Kidney disease is often considered as a family disease due to the intensive care required which can strain the caregivers physical and emotional wellbeing. It is therefore essential to include caregiver experience in the tool.

Patient experience was perceived as highly important for all sites. Some of the factors that were identified as important for patient experience were transport**,** shared decision making and communication.

The importance of the supply chain was discussed, as it takes into account the general world population and how it is impacted. However, it was also mentioned that this should not be the initial priority for the benchmarking tool. These can be explored as secondary or supplementary areas where relevant.

Benchmarking group workshop

All of the groups agreed that patient experience must be included in the tool. The UK Kidney PREMs was seen as useful as it is kidney specific and covers themes like transport which seems to be quite an important aspect of patient experience according to the group. Other patient experience themes that were identified as central to include was shared decision making, equity of access, time spent on treatment, mental health, and the burden of kidney disease.

While staff experience was also perceived as crucial, not many validated surveys were identified which capture staff experience. A few local hospital surveys were discussed.

Several caregiver experience surveys were identified during the workshop including the Carer Impact Scale, Carer Quality of Life Scale, and the Zarit Burden Interview.

There is an agreement that all three elements, patient, staff, and carer experience are important to include in the tool.

The supply chain impact was also discussed briefly, and while the group agreed that it would be useful to see this impact, they thought it could be complex to analyse and include.

Follow-up exercise

In the follow up Google Forms exercise with the clinical sites, the options presented for patient experience were the Kidney PREMs and the HCAHPS, alongside an option for “other”. The results showed that the Kidney PREMs were favored to the HCAHPS.

The exercise also included a section on staff experience, allowing respondents to mention any staff surveys they know of. Two staff surveys came back which were included in the decision-making process.

Respondents were also asked whether the chosen surveys could be conducted at least annually. The result showed that in almost all cases, respondents thought it would be feasible to carry out the surveys at least once a year.

Workshop during the AGM

During the workshop at the AGM, the Kidney PREMs and its shorter version was explored. The shorter version of the PREMs was seen as a useful measure to include in the tool. A few additional questions from the longer version were identified as useful additions. For staff experience, none of the sites opposed to carrying out a staff survey. The two surveys were discussed, one from one of the pilot sites and another from an associate pilot site, and both were seen as useful. One of the sites uses the Areas of Worklife Survey (AWS)[xvi] which is validated for their language, however it incurs some costs. For caregivers, there was an agreement that their experience is extremely important for the monitoring and outcomes of patients as it impacts the patient’s experience and health outcomes. If the results of a caregiver survey show that a carer is unable to cope, sites are able to provide external support to the family, for example, assisted HD, assisted PD, psychological help or directing them to patient associations.

4.2.3. Environmental Impacts

Clinical sites workshop

Environmental impacts in the clinical sites workshop were covered via ranking exercises on Mentimeter. Environmental midpoint categories (e.g. climate change, water use, ecotoxicity) were seen as more useful in supporting a move to more sustainable healthcare than life cycle endpoint impact categories (e.g. human health, ecosystem quality and resource depletion). Amongst the 16 midpoint variables, human toxicity, climate change and water use were seen as the most significant. The group ranked the endpoint variables with human health as the most important, followed by ecosystem quality and lastly resource depletion.

Benchmarking group workshop

During the benchmarking group workshop, a ranking exercise was conducted in the breakout rooms on the 16 environmental midpoint categories. The midpoints identified as the most important were climate change, water use, resource use (both fossils and metals/minerals), human toxicity, ecotoxicity and particulate matter. The SDGs were seen as a useful criterion when looking at environmental impacts, but there were also comments that regulatory or science-based frameworks could be explored.

There was a shared agreement that the ranking of environmental impacts depends on the interest and knowledge of different groups of people. For example, healthcare professionals align with ‘do no harm’ and care about things like human toxicity and climate change, while for healthcare managers cost saving is very relevant hence resource use is seen as more important. On the other hand, policy makers are usually driven by political agendas focusing on political or economic matters that make them more favourable for getting votes. The global society may be more interested in climate change, human toxicity, and particulate matter.

During a Mentimeter exercise exploring whether environmental midpoints or endpoints are more useful to support decision making, endpoints were more favourable to the group.

4.2.4. Costs

Clinical sites workshop

One of the clinical sites mentioned that centre level cost comparisons would be useful. However, also raised the importance of fair comparisons. For example, the comparison should be between kidney centres that operate in a similar way.

A few of the sites mentioned that cost analysis should consider a wide range of factors, including direct healthcare costs (e.g. dialysis, transplantation, equipment, and medication), indirect costs (e.g. lost productivity), and societal costs (e.g. caregiver burden). It is important to compare costs across different healthcare systems and regions to identify potential cost-saving strategies and sustainable practices.

There was a shared view that the benchmarking tool should focus on patients and their caregivers, recognising the significant impact of chronic kidney disease on both. Intangible costs like loss of work and social life, or caregiving due to dialysis is crucial to capture.

One site mentioned that annual treatment pathway costs could be useful and that benchmarking tools should include metrics that kidney centres are comfortable sharing and have readily available.

Benchmarking group workshop

The benchmarking group had varying views on the level for measuring costs. There was an agreement that centre level costs are important. A similar comment to the clinical sites was made about the fairness of centre level comparisons in regard to kidney centres’ size and operating hours. There was also an interest in having treatment pathway costs which would help to identify costs variations and where costs can be saved alongside providing a patient centred approach. However, this needs to be treated sensitively, as it is patients’ medical condition which determines the choice of treatment pathway. There might also be additional costs due to a patients' social situations or mental health.

When exploring the importance of different costs for different healthcare workers, it was agreed that the hospital management would be interested in things like return on investment, long term savings of interventions, tariffs, and staff/patient commute. For staff this picture is slightly different. Costs identified as useful for staff were salaries, travel costs, use of resources and the identification of how interventions could reduce costs. Lastly, for patients, it was agreed that travel costs, days lost from work/ other activities and the use of resources would be useful to capture. As some patients receive PD at home or do home HD, the cost of the use of electricity and housing space would also be useful to understand.

4.3. Data Collection Challenges and Methods to Overcome Them

4.3.1. Challenges and Barriers to Data Collection

Data on health outcomes and social impact

Concerning data collection for health outcomes and social impact, including the use of surveys, the following barriers were identified:

- Some centres/ countries might not want to reveal data due to varying data availability and some data being sensitive (e.g. mortality rates).
- Surveys to collect PROMs and PREMs can be time consuming and repetitive, reducing patient engagement.
- Patients are going through intensive treatment, some can be depressed etc., and filling in surveys could be an additional burden.
- There might be a lack of digital literacy among elderly dialysis patients which means that using phones and iPads might be an issue and the surveys might need to be carried out with paper, or with a nurse etc.
- Staff are often under time pressure which makes it difficult to set aside time to do or introduce the surveys to patients.
- Not all of the surveys explored are validated in the KNC sites language. However, there is a question whether validation is a necessity for the project.
- Patient reported outcomes and experience are different, experience produces different outcomes in different patients even with the same clinical circumstances, so it is difficult to interpret.

Data on environment impact and costs

The barriers that exist in sharing data on resource use, waste and travel were identified as:

- Data being commercially confidential causing sensitivity and lack of ability to share.

- Electricity, water, and waste are often measured at the hospital level, not at the kidney centre level, which makes it difficult to allocate to specific areas.
- Quantifying resource data for home treatment will be difficult.
- While management often uses cost data for decision making, they do not share data with staff. When staff don't know cost breakdowns, it is difficult for them to identify areas for improvement.

4.3.2. Methods Identified to Help to Overcome Barriers

Data on health outcomes and social impact

Some of the approaches identified to overcome barriers in health outcomes and social impact data collection were:

- Considering opportunities for automation or leveraging existing data downloads from either internal or external sources, to streamline the process.
- During the piloting of the tool, the initial data collection exercise might have a huge database. While some might prefer this, others would prefer narrowing down and looking at the most important datasets. There could be a possibility of having a light versus complex version of the tool. If data can be automated, there can be a bigger tool.
- It would be useful to have additional administrative support for conducting surveys.
- The possibility of asking a patient to become a part of the research team could be explored, where the patient representative could talk to other patients and help them fill in surveys.
- Considering biannual surveys rather than annual, to ease the burden on patients and staff.
- Considering shorter surveys rather than longer ones to reduce the burden on staff and patients.

Data on environment impact and costs

Some of the ideas identified to simplify data sharing for resource use, water and travel were:

- Having central recording systems within a unit which then translates to resource use and distance travelled etc.
- Asking for consent to data collection at admission's stage including patient travel data which can then be used.
- Conducting initial studies can help determine which data points are most difficult to collect and develop standardised methods to address those gaps. Guidance can be created, which outlines steps that need to be followed for data collection.
- Prepopulating with data from existing datasets.

- Having requirement for units to routinely report data centrally- either regionally or nationally, will help with data being available and ready to use.
- Concerning productivity loss: Estimation of average cost of time lost based on average wages.

Supply chain

The ideas that were discussed to simplify data collection for the supply chain were:

- Looking at supplier details: there should be collective action to engage suppliers in reporting on environmental sustainability and it falls within the clinical site's responsibility to ask for sustainable requirements when deciding on the supplier.
- Doing an analysis on a sample of goods as a proxy.
- Basing data on units or volumes of items and not costs.
- Having automatic calculations.
- Focusing on certain areas e.g. most resource intensive areas.
- Following the British Standards Institute (BSI) framework for medicines and pharmaceuticals.

4.4. Additional Insights from Mentimeter Exercises

Clinical sites workshop

Treatment pathway impact measures seem to be more important than centre level for decision making according to the clinical sites.

The EQ-5D-5L and KDQOL 36 are popular surveys amongst the group when used for studies like clinical trials.

When ranking the impact measures - environmental, social and costs- in order of importance, environmental scored higher than the other impact categories.

Benchmarking group workshop

There were mixed views at which level impact measures would be most useful. Looking specifically at health professionals, the group thought, impact measures at treatment pathway level are most important. Yet, for healthcare managers, they thought comparison at whole centre level would be most beneficial. Thinking specifically about policy makers, impact measures at the level of the whole centre and treatment pathway had an equal result.

Some of the systemic and cultural barriers which were identified as potentially impacting the adoption and effectiveness of the tool were: absence of policy support, lack of sustainability awareness, lack of time, lack of knowledge, and complexities involved.

Some of the methods which were mentioned as overcoming these cultural and systemic barriers were: staff and patient education/ training, making the tool easy to use, engaging policy makers early on, emphasising cost savings and providing support to implement it.

5. Conclusions

5.1. Key Outcomes

For health outcomes, there was a shared agreement in survival rates being useful to include in the tool. Other measures suggested for inclusion were prevalence rates, transplantation rates, hospitalisation rates and infection rates. QoL/ PROMs are also perceived as important, with the KDQOL SF 12 being the preferred option to use upon the final workshop conducted in Madrid.

Patient, staff, and carer experience are all important social impacts to include in the tool. The key themes identified for patient experience are transport, shared decision making and equity of access. The shorter version of the Kidney PREMs is preferred over other measures to assess patient experience. Staff and carer surveys need to be looked into in further detail to confirm the optimal ones to use. Supply chain impacts are useful but should not be the focal point of the tool in the first iteration.

There is a general agreement that climate change, human toxicity, resource use (both fossils and metals/minerals) and water use are important from the midpoint measures, and human health and ecosystem quality are important from the endpoint measures. For the clinical sites the midpoints were more important and therefore these will be included in the benchmarking tool. We will also consider if endpoints could be added too.

The tool will cover centre level comparisons and pathway level comparisons. This will allow costs to be compared on both centre level and pathway level. There is an agreement that the tool should encompass both direct costs and indirect costs, such as loss in labour productivity as this is a huge impact of kidney disease. Other costs that are important to include are return on investment, staff/ patient travel and resource use.

The measures are summarised in the table below.

Health Outcomes	Social Impact	Environmental Impacts	Costs
Survival rates	Patient experience via the Kidney PREMs survey	Climate change	Overall costs for centre level and pathway level
Prevalence rates	Staff experience- survey to be confirmed	Human toxicity	Resource costs
Transplantation rates	Carer experience- survey to be confirmed	Resource use (fossils, metals, and minerals)	Patient and staff travel
Emergency admissions/ hospitalisation rates		Water use	Loss of labour productivity
Infection rates			Return on investment
QoL via the KDQOL SF 12 survey			

Finally, methods to overcome barriers in data collection are having central recording systems and automation, leveraging existing datasets, and conducting studies to determine gaps to produce a guide. For overcoming barriers in collecting surveys, the main suggestions are having administrative support to conduct the surveys, including the possibility of a patient representative leading on the task.

5.2. Next Steps

We will work with Work Package 2 on the data entry requirements for the environmental impact assessment for the benchmarking tool, based on the preliminary LCA results for PD and HD.

Staff and caregiver experience measures will be agreed via a Google Forms voting exercise with the clinical sites.

The Work Package 5 team will be working with the software developer partners of the project, 040, to progress on the technical development of the benchmarking tool. During this phase, the measures to use on the tool will be finalised. The discussions on the technical development of the tool will also include data input methods and balancing ease of use.

The first version of the tool will be delivered in June 2025 and the piloting will commence in July 2025.

6. Appendix

6.1. Questions Discussed During Workshops

Clinical sites workshop

Facilitators: Aycan Yasar, Ingeborg Steinbach, Harriet Attwell- Rogers, Brett Duane, Anita Griffin, Bridget Johnston

Health outcomes

1. *What health outcomes indicators do you currently collect, e.g. incidence, prevalence of ESKD, rate of transplant?*
2. *What process outcomes do you currently collect, e.g. rates of emergency admissions, rates of infection*
3. *Which additional health outcomes would it be useful to track?*
    a. *From the health professionals perspective*
    b. *From the patients' perspective*

Social impact

1. *For which population group should the benchmarking tool measure/display social impact for: patients, caregivers, staff, supply chain or all? Rank them as a group.*
2. *Are you currently measuring any social impact on these groups? What tool(s) do you use?*
3. *If we think of patient experience indicators which ones do you think are the most important, e.g. shared decision making, support by renal team, communication?*
4. *If you think of the staff which social impact should the benchmarking tool consider?*

Costs

1. *At what level would you like the benchmarking tool to measure costs?*
    a. *Annual cost of centre*
    b. *Annual cost or treatment pathway*
    c. *Annual cost of implementing intervention?*
    d. *Annual economic cost (healthcare plus cost of illness)*
    e. *All of the above*

2. *What elements/cost centres are you already collecting and are able to share?*

Benchmarking group workshop 1

Facilitators: Aycan Yasar, Ingeborg Steinbach, Harriet Attwell- Rogers, Anita Griffin, Marta Arias

Health outcomes

1. *The European Renal Registry routinely collects the following data:*
    - *Patient survival on dialysis*
    - *Patient survival after transplant and graft survival, from deceased donor or living donor*
    - *Expected remaining years of life for patients on dialysis and patients with transplant*
    - *Incident patients accepted for KRT (at day 1), and prevalence rates*
    - *Rates of transplant, from deceased donor or living donor*

2. *Should our benchmarking tool align with the ERA and display these health outcomes? Which of these would be most useful to include in the tool? What other measures might be missing and useful to include?*
3. *Do you think it would be useful for the benchmarking tool to collect additional process outcomes? (e.g. bacteraemia/ peritonitis rates, emergency admission rates). Which process outcomes would be a useful addition?*
4. *From your experience, which QoL measures/ PROMs captures the impact of kidney disease and treatment on the patient best and why? (e.g. EQ-5D-5L, KDQOLSF)*
5. *What additional measures do you have experience with, that could be useful for the benchmarking tool?*
6. *Practicality of the measures mentioned: What barriers might there be in collecting health outcomes and quality of life measures once a year? How do you think we can overcome them?*

Social impacts

1. *Which patient experience measures do you think are useful to collect?*
    a. *Kidney PREMS*
    b. *HCAHPS*

2. *Which staff satisfaction surveys have you got experience with that could be useful?*
3. *Which carers experience questionnaires have you got experience with that could be useful?*
4. *Which of the experience measures do you think would be important for the benchmarking tool to include? Patient, staff and carers experience? Are there other social impact indicators that would be important for the benchmarking tool to report on, e.g. equity of access to care?*
5. *What barriers might there be in carrying out these surveys once a year? How do you think we can overcome them?*

6. *What are your thoughts of including the social impact of the supply chain within the benchmarking tool? If you think it would be useful for the benchmarking tool to collect and display these social impacts, which ones should we include?*

   Some of the impacts from supply chain include

   - *Child labour*
   - *Fair salary*
   - *Violations of employment laws and regulations*
   - *Goods produced by forced labour*
   - *Fatal and/or non-fatal accidents*
   - *Education*
   - *Corruption*
   - *Industrial water depletion*
   - *Trafficking in persons*

Benchmarking group workshop 2

Facilitators: Aycan Yasar, Ingeborg Steinbach, Harriet Attwell-Rogers, Frances Mortimer, Marta Arias, Brett Duane

Environmental impacts

1. *Please rank the top 5-6 midpoint measures as a group in order of importance to making the case for sustainable healthcare interventions. What criteria should be used for ranking? E.g. alignment with Sustainable Development Goals?*

   - *Midpoint impacts:*
   - *Climate change*
   - *Ozone depletion*
   - *Human toxicity*
   - *Particulate matter*
   - *Ionizing radiation*
   - *Photochemical ozone formation*
   - *Acidification*
   - *Eutrophication (terrestrial)*
   - *Eutrophication (freshwater)*
   - *Eutrophication (marine)*
   - *Land use*
   - *Ecotoxicity, freshwater*
   - *Water use*
   - *Resource use (fossil)*
   - *Resource use (minerals and metals)*

2. *Looking at the results of the ranking, how do you think it would differ for different professional groups e.g. healthcare professionals, healthcare managers and policy makers.*

3. *The preliminary PD results identify the main contributors to the environmental impact of PD. How can we simplify data collection for these contributors (patient travel, staff travel, electricity use, water use and waste disposal)? (Supply chain will be covered in the next question).*

4. *The environmental impact of the supply chain is notorious difficult/time consuming to measure. How can the benchmarking tool capture the impact of the supply chain itself and any sustainability improvements within the supply chain without requiring extensive data collection?*

Costs

1. *At which level would measuring costs be more useful for the benchmarking tool? (e.g. cost at centre level, treatment pathways, implementation of intervention)*
2. *What type of costs are useful for the hospital management to make decisions? (e.g. whole economic cost including loss of labour) How could the benchmarking tool balance short-term costs and long-term environmental or economic benefits.*
3. *What type of costs would patients and staff find useful?*
4. *What barriers do you think there may be on sharing costs and how do you think these can be overcome?*

Workshop during the AGM

Facilitators: Aycan Yasar, Ingeborg Steinbach

PROMs/QoL

1. *Which survey (EQ-5D-5L, KDQOL SF 36, KDQOL SF 12) would be more practical and easier to carry out annually at your hospital to feed into the benchmarking tool? Why?*

2. *The 4 impact results of the individual kidney centres will only be visible to the individual centre. What barriers might you face in sharing the PROMs result on the benchmarking tool?*

PREMs

1. *Which survey (EQ-5D-5L, KDQOL SF 36, KDQOL SF 12) would be more practical and easier to carry out annually at your hospital to feed into the benchmarking tool? Why?*

2. *The 4 impact results of the individual kidney centres will only be visible to the individual centre. What barriers might you face in sharing the PROMs result on the benchmarking tool?*

Staff experience

1. *Which of the staff surveys captures better staff experience and satisfaction? Why?*

2. *What barriers might be at your organisation to conduct a staff survey?*

Caregiver experience

1. *How would you use the results of the survey?*

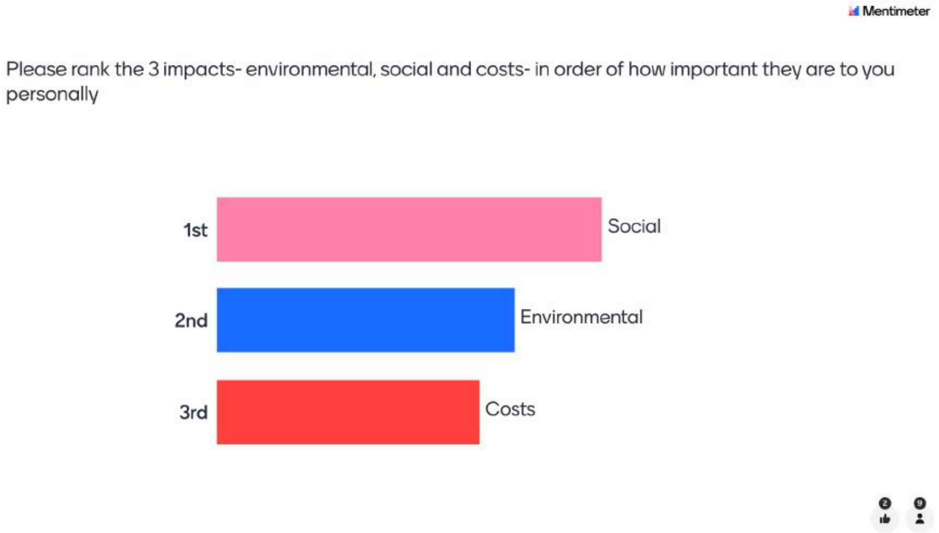
2. *What kind of support would you be able to offer the caregivers*

General discussion

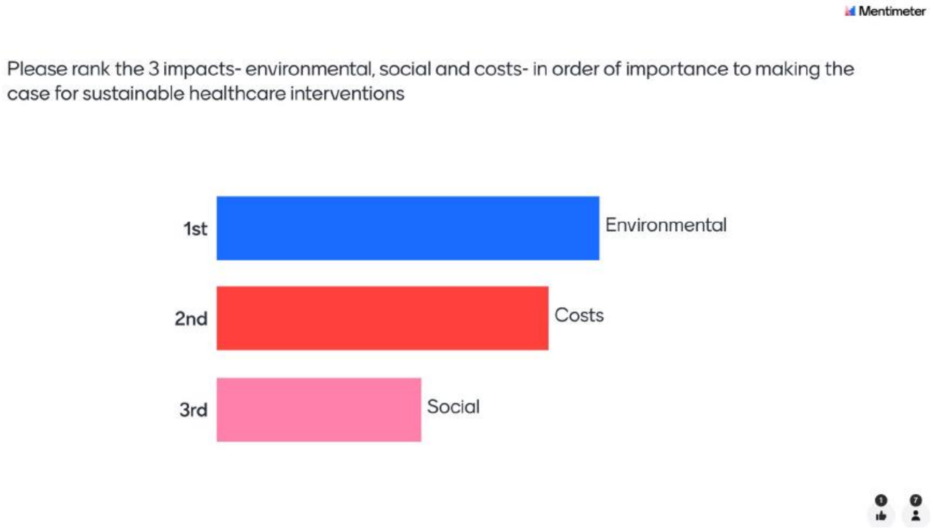
1. *How would you organise the survey? What information and assistance do you need?*
2. *How much capacity do you think you have to carry out the surveys annually? If you do not think you have enough capacity, what resources might you be able to draw on to be able to conduct the surveys?*

6.2. Mentimeter Results

Clinical sites workshop



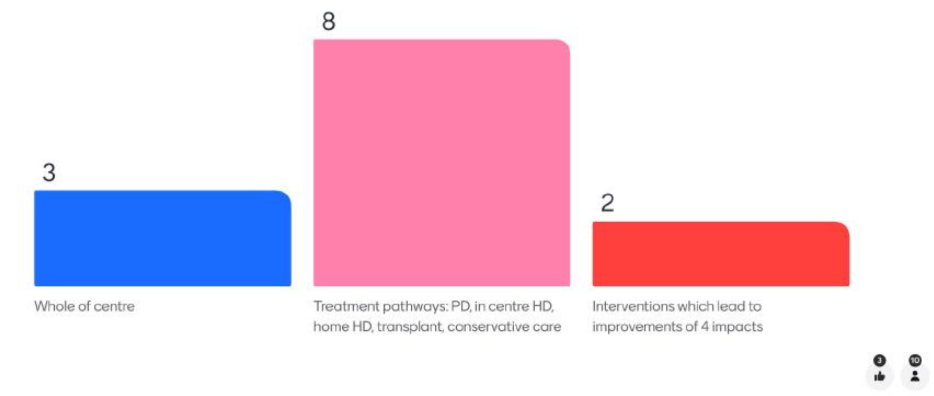
Please rank the 3 impacts- environmental, social and costs- in order of how important they are to you personally



Please rank the 3 impacts- environmental, social and costs- in order of importance to making the case for sustainable healthcare interventions

Mentimeter

At what level do you think the 3 impact measures can be most useful for decision making? Choose as many as applicable

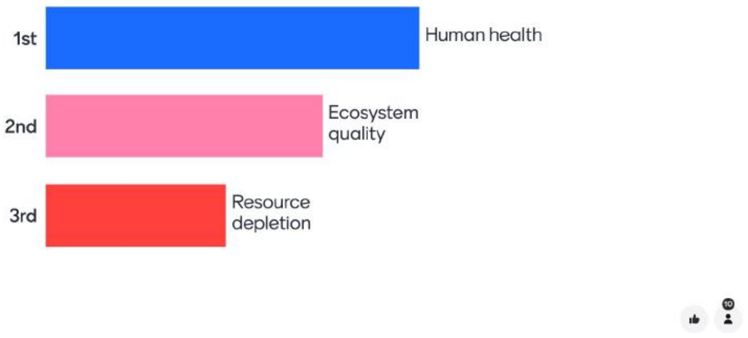


Mentimeter

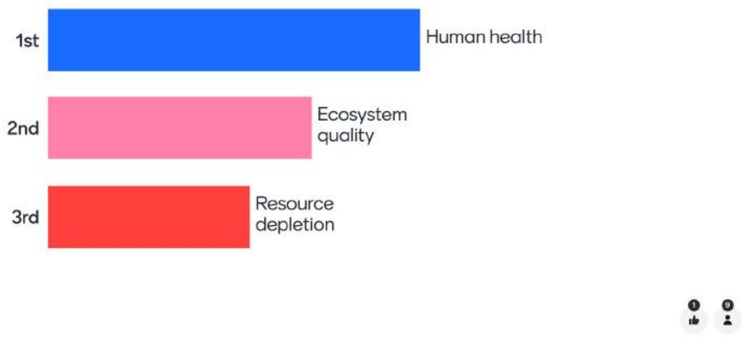
Which Quality of Life (QoL) measures and/or Patient Reported Outcome Measures (PROMs) do you currently collect? Please choose the ones applicable

Mentimeter

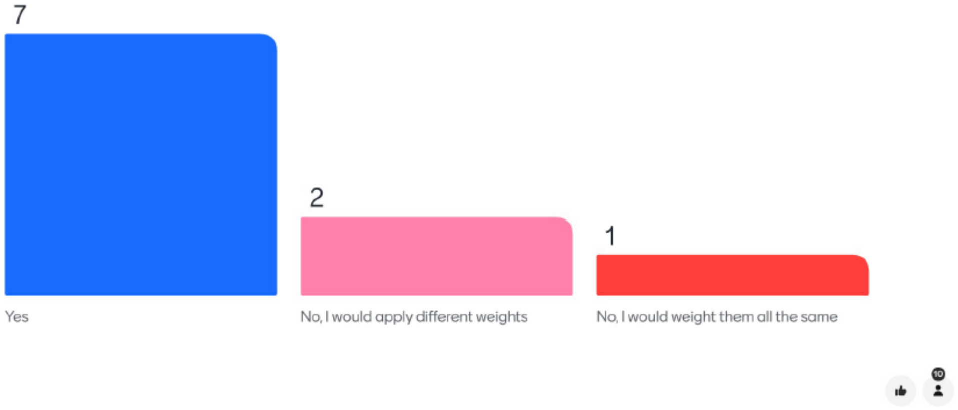
Please rank the 3 life cycle endpoint impact categories in order of how important they are to you personally



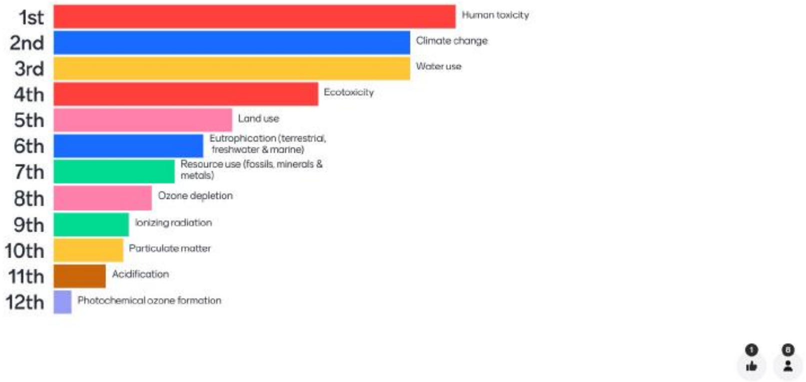
Please rank the 3 life cycle endpoint impact categories in order of importance to making the case for sustainable healthcare interventions

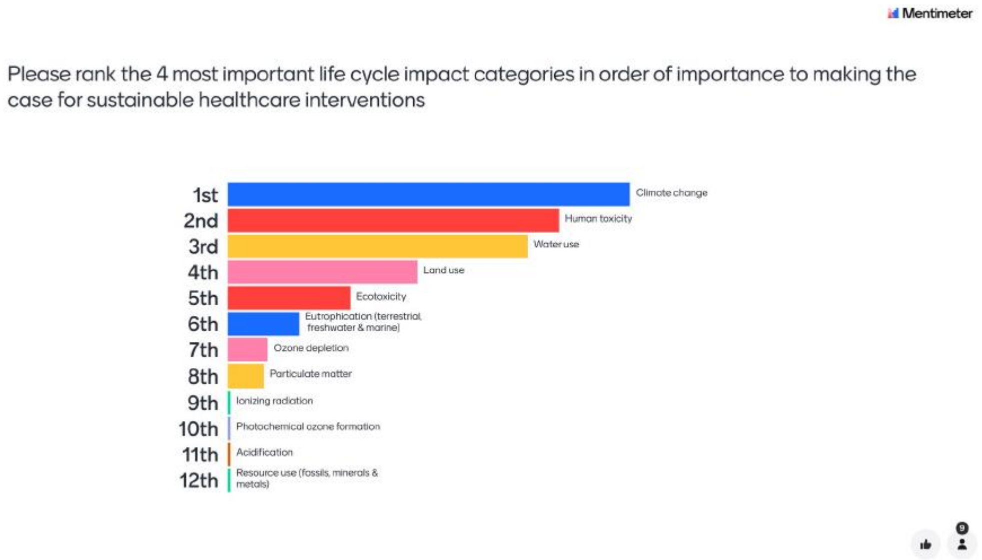


Do you agree with the weighting of the 3 endpoints in the article: Human health 0.41, ecosystem quality 0.31 and resource depletion 0.26?

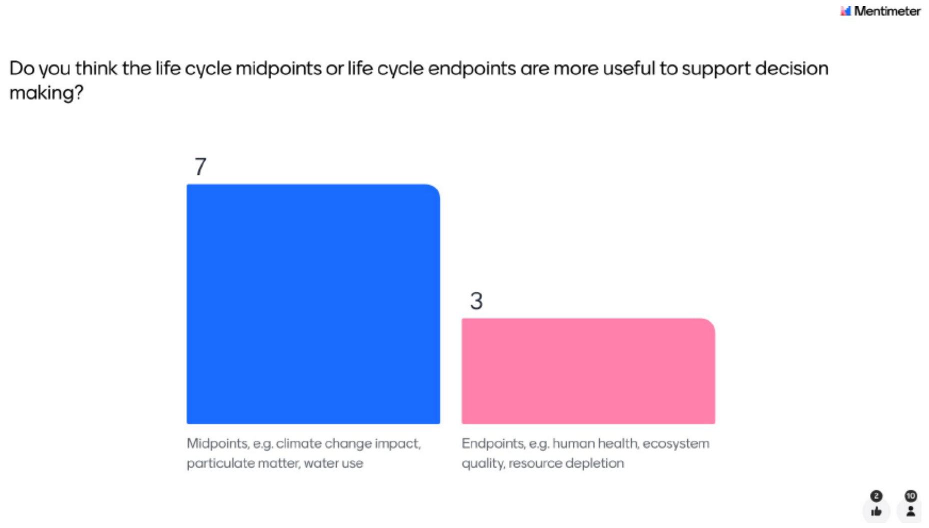


Please rank the 4 most important life cycle impact categories in order of how important they are to you personally

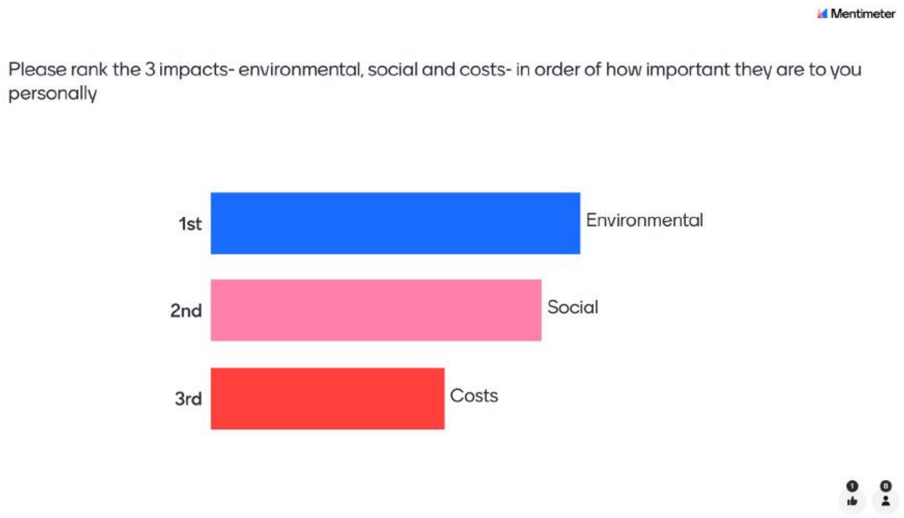




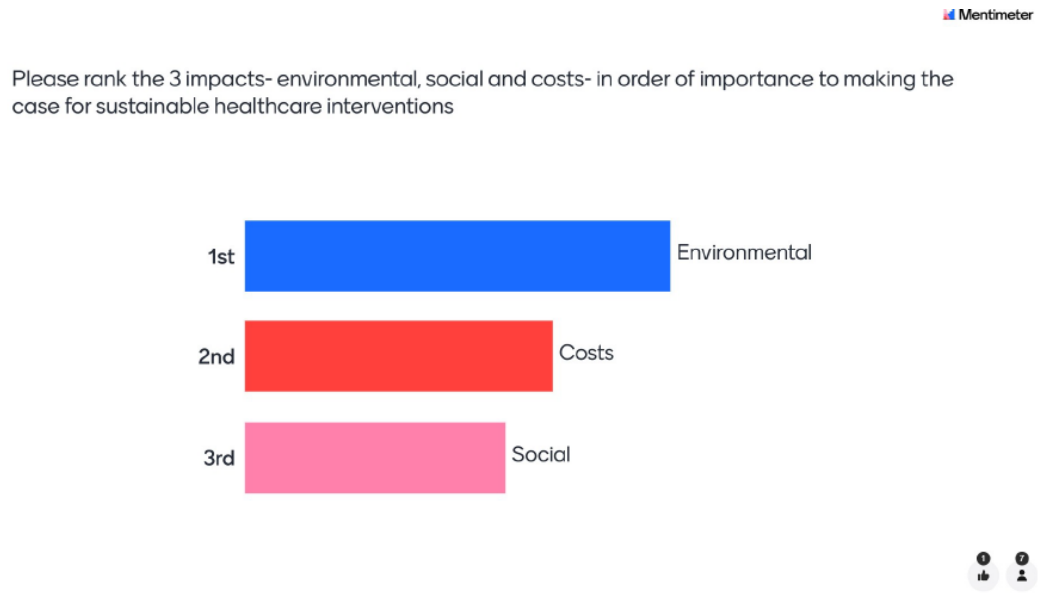
Please rank the 4 most important life cycle impact categories in order of importance to making the case for sustainable healthcare interventions

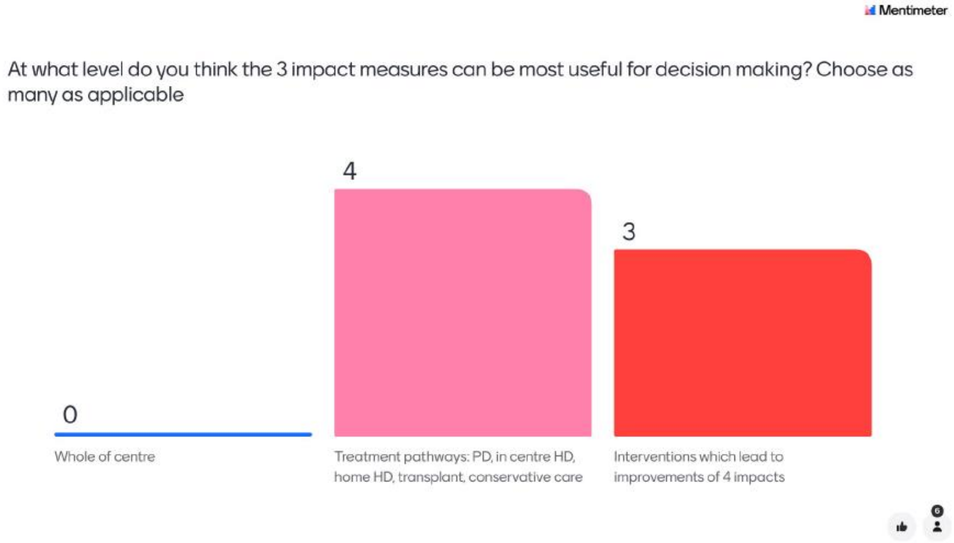


Do you think the life cycle midpoints or life cycle endpoints are more useful to support decision making?

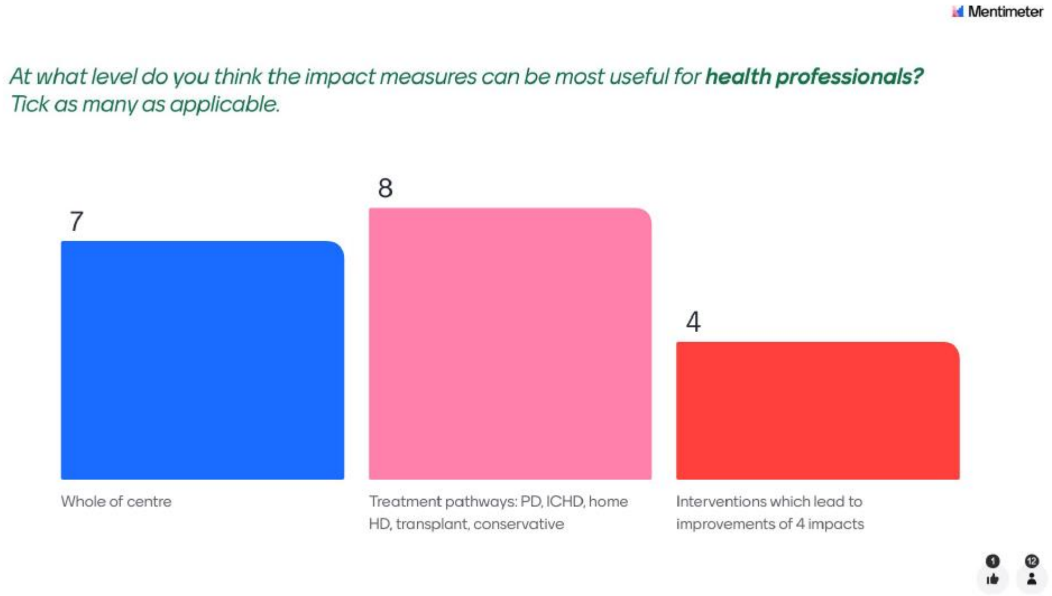


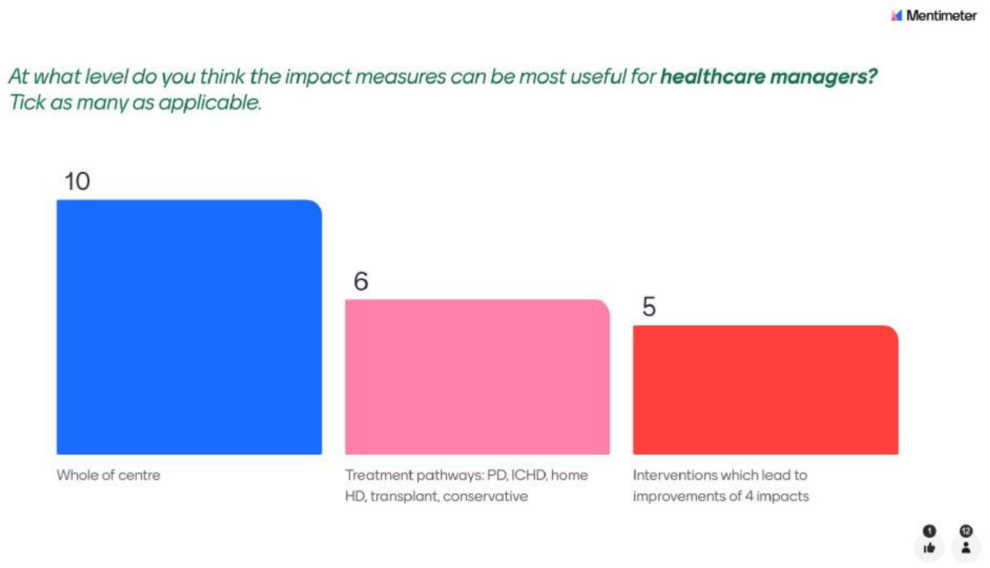
Please rank the 3 impacts- environmental, social and costs- in order of how important they are to you personally


Please rank the 3 impacts- environmental, social and costs- in order of importance to making the case for sustainable healthcare interventions

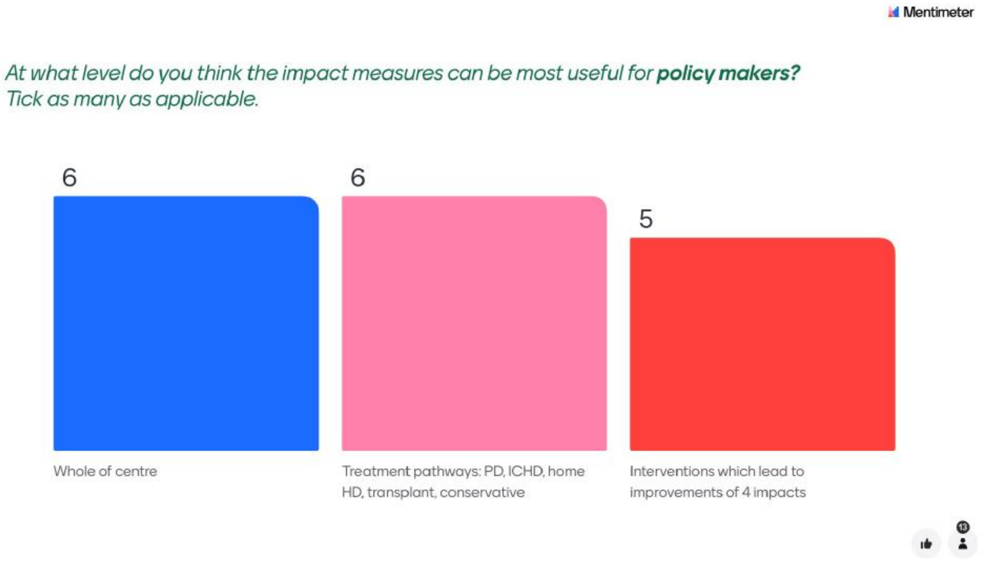

At what level do you think the 3 impact measures can be most useful for decision making? Choose as many as applicable

Benchmarking group workshop 1


*At what level do you think the impact measures can be most useful for **health professionals?** Tick as many as applicable.*

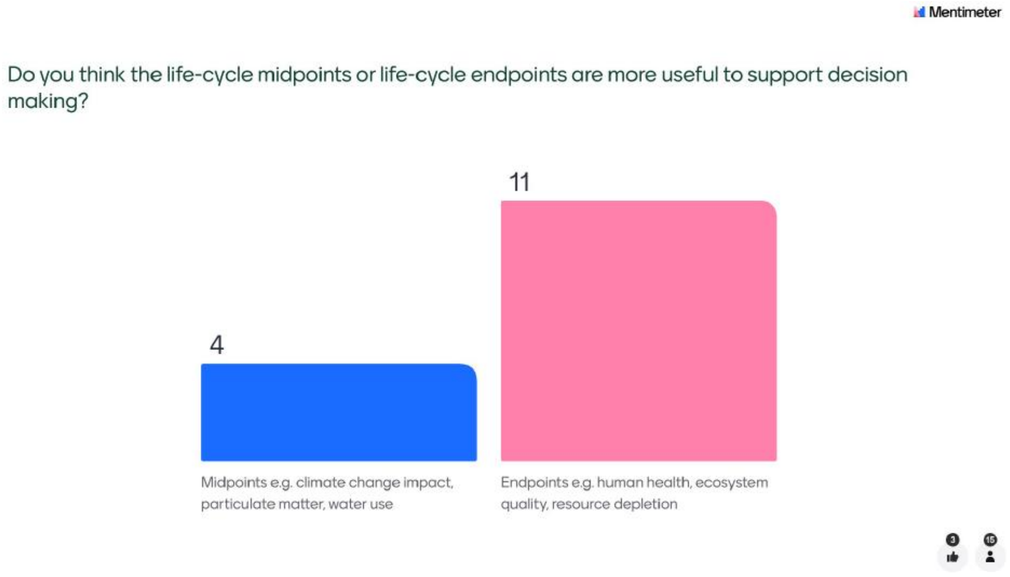


At what level do you think the impact measures can be most useful for ***healthcare managers?***
Tick as many as applicable.

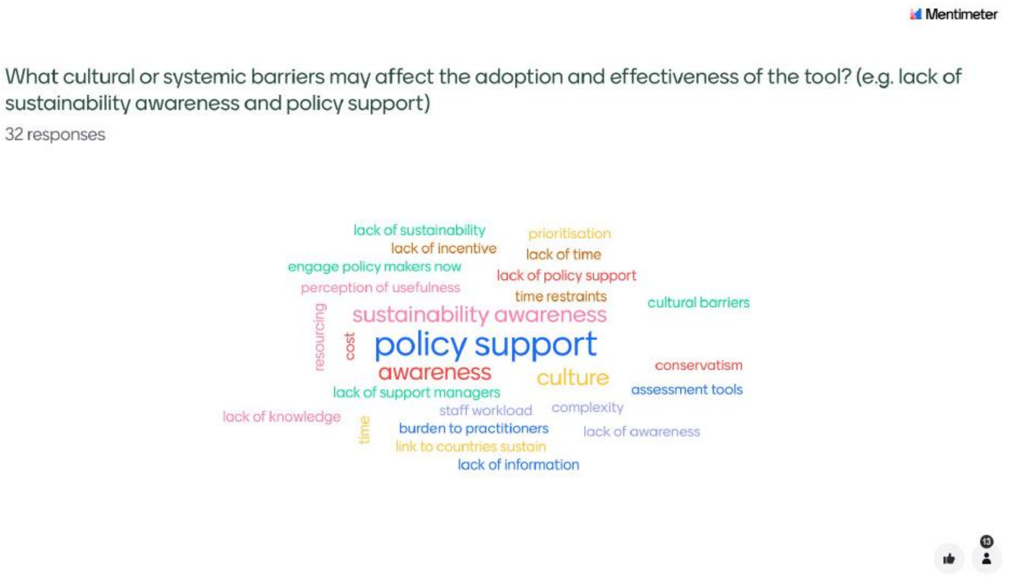


At what level do you think the impact measures can be most useful for ***policy makers?***
Tick as many as applicable.

Benchmarking group workshop 2



Do you think the life-cycle midpoints or life-cycle endpoints are more useful to support decision making?



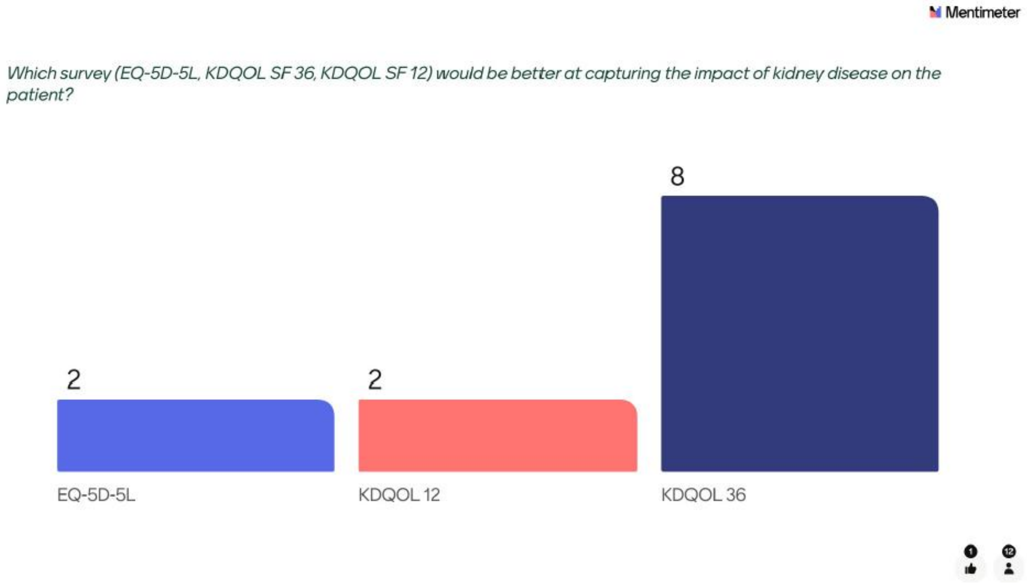
What cultural or systemic barriers may affect the adoption and effectiveness of the tool? (e.g. lack of sustainability awareness and policy support)

32 responses

How could we overcome these barriers?

29 responses

Workshop during AGM



Which survey (EQ-5D-5L, KDQOL SF 36, KDQOL SF 12) would be better at capturing the impact of kidney disease on the patient?

7. References

---

[i] European Renal Association (ERA) ERA reports and guidelines. Available at: https://www.era-online.org (Accessed: 24 March 2025).

[ii] Getting It Right First Time (GIRFT) GIRFT national specialty reports. NHS England. Available at: https://gettingitrightfirsttime.co.uk (Accessed: 24 March 2025).

[iii] EuroQol Group (2009) EQ-5D-5L: A standardized instrument for measuring generic health status. Available at: https://euroqol.org (Accessed: 24 March 2025).

[iv] Hays, R.D., Kallich, J.D., Mapes, D.L., Coons, S.J. and Carter, W.B. (1994) 'Development of the kidney disease quality of life (KDQOL) instrument', Quality of Life Research, 3(5), pp. 329–338. doi:10.1007/BF00451725.

[v] Bradley, C. (1997) 'Design of a renal-dependent individualized quality of life questionnaire', Advances in Peritoneal Dialysis, 13, pp. 116–120. PMID: 9360663

[vi] UK Kidney Association Patient reported experience measures (PREMs) survey results. Available at: https://ukkidney.org (Accessed: 24 March 2025).

[vii] Centers for Medicare & Medicaid Services (CMS) (2021) Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey. Available at: https://www.hcahpsonline.org (Accessed: 24 March 2025).

[viii] Zarit, S.H., Reever, K.E. and Bach-Peterson, J. (1980) 'Relatives of the impaired elderly: Correlates of feelings of burden', The Gerontologist, 20(6), pp. 649–655. doi:10.1093/geront/20.6.649.

[ix] Brouwer WB, van Exel NJ, van Gorp B, Redekop WK. (2006) The CarerQol instrument: a new instrument to measure care-related quality of life of informal caregivers for use in economic evaluations. Qual Life Res. Aug;15(6):1005-21

[x] Novak, M. and Guest, C. (1989) 'Application of a multidimensional caregiver burden inventory', The Gerontologist, 29(6), pp. 798–803. doi:10.1093/geront/29.6.798.

[xi] Eisfeldt, F (2017) Soca v.1 add-on- Adding social impact information to ecoinvent. Description of methodology to map social impact information from PSILCA v.1 to ecoinvent v.3.3. GreenDelta. Available at: https://nexus.openlca.org/documents (Accessed: 24 March 2025).

[xii] European Commission. Energy, climate change and environment. Life Cycle Assessment & the EF methods. Available at: https://green-business.ec.europa.eu/environmental-footprint-methods/life-cycle-assessment-ef-methods_en (Accessed: 24 March 2025).

[xiii] Goedkoop, M., Heijungs, R., Huijbregts, M.A.J., De Schryver, A., Struijs, J., and Van Zelm, R. (2009) ReCiPe 2008: A life cycle impact assessment method which comprises harmonised category indicators at the midpoint and the endpoint level. First edition Report I: Characterisation. National Institute for Public Health and the Environment (RIVM).Available at: https://www.rivm.nl/sites/default/files/2018-11/ReCiPe%202008_A%20lcia%20method%20which%20comprises%20harmonised%20category%20indicators%20at%20the%20midpoint%20and%20the%20endpoint%20level_First%20edition%20Characterisation.pdf (Accessed: 24 March 2025).

[xiv] Ecoinvent Centre Ecoinvent database: Life cycle inventory data for sustainability assessments. Available at: https://www.ecoinvent.org (Accessed: 24 March 2025).

[xv] United Nations (2015) Sustainable Development Goals (SDGs). Available at: https://sdgs.un.org (Accessed: 24 March 2025).

[xvi] Maslach, C. and Leiter M.P. (2003) *Areas of Worklife Survey*. Mind Garden, Inc.