Toolkit To Map Your Living Kidney Donor Assessment Pathway

CENTRE *for* SUSTAINABLE HEALTHCARE

UKKA
UK Kidney Association

The Health Foundation

NHS
Blood and Transplant

Contents

Introduction

Introduction

Who this toolkit is for

This document and associated tools are designed for healthcare teams, managers and staff responsible for the delivery of Living Kidney Donor (LKD) Assessment services. Provision of this toolkit builds on Phase 1 of the project, which mapped the LKD assessment pathways across three services to identify variations, estimate environmental impacts, and highlight sources of inequity. It incorporates learning from Phase 1 to help LKD services scale and extend this work.

Link to Report

Why use it

The impacts of climate change are increasing globally (1), with the way we deliver healthcare significantly contributing to the global crisis. The NHS has a significant environmental impact, producing 4-5% of the UK's overall greenhouse gas emissions (GHG) 20-25 million tonnes of carbon dioxide equivalent (CO2e) per year (2), greater than the annual emissions from all aircraft departing from Heathrow airport (3). The NHS has set a target of reaching net zero carbon emissions by 2045 (4) and transforming care pathways is a crucial part of delivering against this goal. The use of this toolkit, along with the proposed changes, offers opportunities to enhance donor care and experience, and increase the sustainable value of the living donor assessment pathway by improving outcomes and reducing the environmental, social and financial impact.

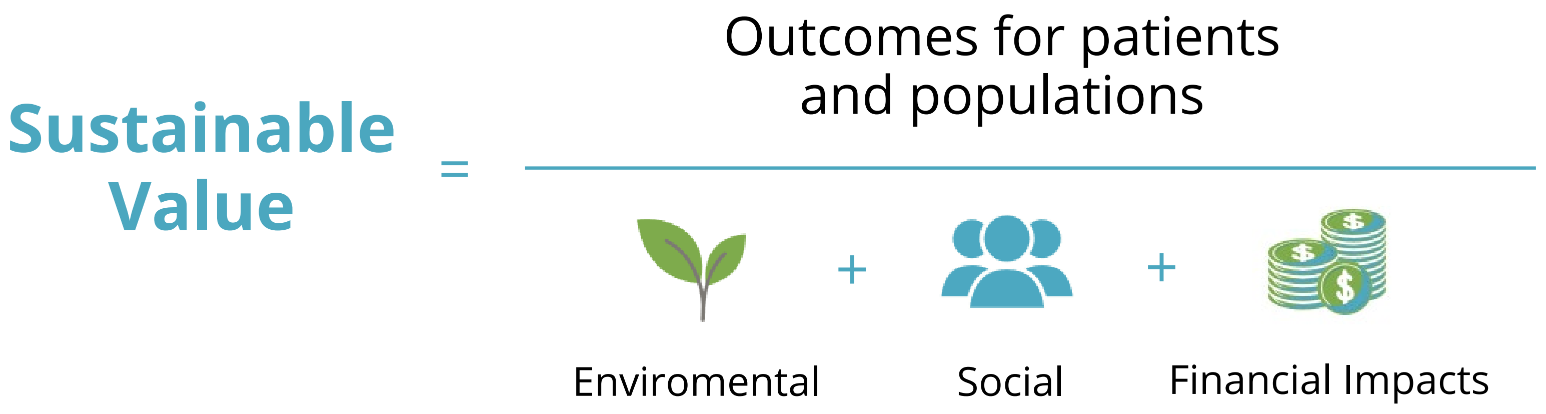

Fig 1. Sustainable value in healthcare (5)

How to Use

This toolkit provides a step-by-step approach to help you conduct pathway analysis in your own setting. It includes:

- An example case study
- Practical tools
  1. **Pathway measurement tool, with carbon calculator**
     **Key resource*
  2. Engaging stakeholder guidance
  3. Involving people with lived experience guidance
  4. Understanding your donor population guidance

  (For 2,3 & 4 - It's strongly advised you consider all these factors and use this guidance, however, if you feel confident already in these processes, it is not essential to use these three grey resources)
- Examples of high-impact changes to consider implementing in your setting.
- A case study template to help you document and share your learning.

Developed with input from clinical experts and lived experience representatives, this guide is designed to support you in improving outcomes while reducing environmental impact.

Example Case Study

CENTRE *for* SUSTAINABLE HEALTHCARE

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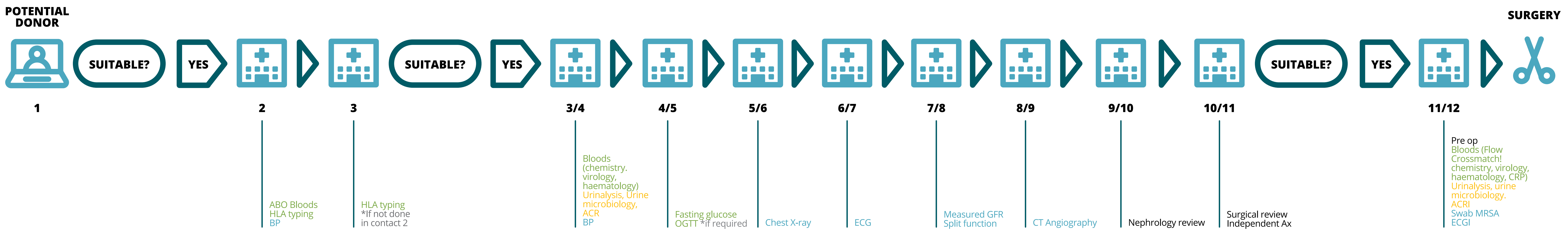
The Health Foundation

NHS Blood and Transplant

Example Case Study

Bradford LKD service undertook a review of their LKD assessment pathway and resource use.

Before



POTENTIAL DONOR

SUITABLE? → YES

SURGERY

1

2
ABO Bloods
HLA typing
BP

3
HLA typing
*If not done
in contact 2

SUITABLE? → YES

3/4
Bloods
(chemistry.
virology,
haematology)
Urinalysis, Urine
microbiology,
ACR
BP

4/5
Fasting glucose
OGTT *if required

5/6
Chest X-ray

6/7
ECG

7/8
Measured GFR
Split function

8/9
CT Angiography

9/10
Nephrology review

10/11
Surgical review
Independent Ax

SUITABLE? → YES

11/12
Pre op
Bloods (Flow
Crossmatch!
chemistry, virology,
haematology, CRP)
Urinalysis, urine
microbiology.
ACRI
Swab MRSA
ECGI

The pathway maps appointments and key decision points from initial contact up to and including the pre-operative appointment. A ‘typical pathway’ is depicted, excluding variations for a small proportion of donors who require additional investigations

All activities were recorded per contact and their environmental impact calculated across travel, tests, diagnostics, sample transport and utilities. Data was converted into GHG emissions. A ‘typical’ pathway produced **112.9kgCO2e**, with donor travel making up **54%**

12
Appointments

The carbon footprint
of a ‘typical’ LKD
assessment pathway
per donor was

112.9 $\mathrm{kgCO_2e}$

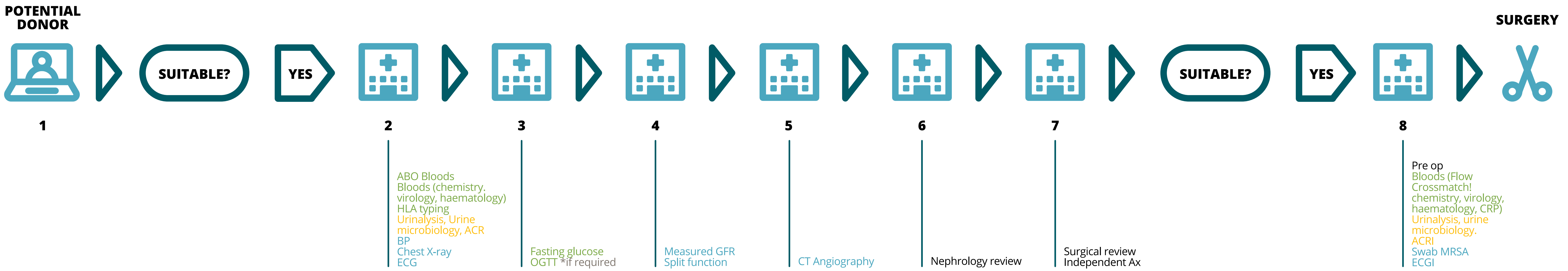
Average distance
travelled

243 miles

Example Case Study

Bradford LKD service undertook a review of their LKD assessment pathway and resource use.

After



POTENTIAL DONOR

1

SUITABLE?

YES

2

ABO Bloods
Bloods (chemistry. virology, haematology)
HLA typing
Urinalysis, Urine microbiology, ACR
BP
Chest X-ray
ECG

3

Fasting glucose
OGTT *if required

4

Measured GFR
Split function

5

CT Angiography

6

Nephrology review

7

Surgical review
Independent Ax

SUITABLE?

YES

8

Pre op
Bloods (Flow Crossmatch! chemistry, virology, haematology, CRP)
Urinalysis, urine microbiology.
ACRI
Swab MRSA
ECGI

SURGERY

Following review of the assessment pathway and resource use, the team identified they could reduce the number of appointments by offering blood, urine and cardiovascular screening tests within Contact 2.

The new, streamlined pathway has reduced the number of appointments from 12 to 8, lowering GHG emissions from **112.9 kgCO2e** to **92.3 kgCO2e** per donor.

8
Appointments

The new streamlined pathway reduced the carbon footprint per donor to

92.3 kgCO_2e

Average distance travelled

158 miles

Toolkit

Toolkit

1 Engaging Stakeholders and Forming Your Team

2 Involving People with Lived Experience

3 How to Map your Pathway and Resource Use

Step by Step Guidance

4 Understanding your donor population guidance

1. Engaging Stakeholders and Forming Your Team

Introduction

Effective healthcare improvement requires engaging the right stakeholders and forming a dedicated team. This guidance provides a structured approach to stakeholder engagement and team formation to assess and optimise your existing healthcare pathway successfully.

Toolkit - 1. Engaging Stakeholders and Forming Your Team

Identifying and Engaging Stakeholders

1.1 Who are the Key Stakeholders?

Engaging a diverse set of stakeholders ensures comprehensive understanding and buy-in. Stakeholders should include representation from each role involved in the process, and may include:

- **Healthcare professionals/ delivery staff**: e.g. medical staff, nurses, transplant co-ordinators, radiologists, medical physics, allied health professionals, healthcare assistants
- **Donors, patients, families and carers**: Those directly affected by the healthcare pathway
- **Administrative and leadership teams**: Hospital/ service managers, department heads, administration staff
- **Policy makers, commissioners, regulators***: National /Regional bodies, ICS leads, accreditation bodies.

**If relevant – these are people that may require to be involved when making changes that impact the system, you may want to advise, keep informed or may need to include depending on scale of change.*

You can use this stakeholder mapping template for guidance (optional) to first list all your stakeholders (Tab 1) This uses the '9 Cs' to ensure that you have included all relevant stakeholders. Then you can use the stakeholder matrix (Tab 2) to identify each stakeholder's level of influence and impact which will help you to know how to engage them.

1.2 Stakeholder Engagement Strategies

- **Early Involvement**: Engage stakeholders from the start to encourage buy-in.
- **Clear Communication:** Establish clear objectives, expectations, and benefits.
- **Regular Feedback Mechanisms**: Use focus groups, meetings, update emails, shared document platforms (e.g. Microsoft Teams folder, Sharepoint).
- **Collaborative Decision-Making**: At the point of considering changes facilitate shared decision-making sessions.

1.3 Forming the Right Team

Considering all stakeholders is important and you will need to decide who to keep informed and how. You will also need a core team (ideally 3-6 people) to carry out the pathway mapping and make and monitor any changes.

Selecting Team Members
A multidisciplinary team enhances problem-solving and improvement. Key members include:

- **Clinical Leaders and staff**: Provide insight into best practices - those who are closest to process. (e.g. Transplant coordinator, surgeon, nephrologist, radiologist, ward manager.
- **Lived Experience representatives** : Ensure views and experiences are captured and servicer user - centred care of any changes.
- **Quality Improvement Team**: You may have access to experts in improvement methodologies through your Quality Improvement team.
- **Administrative support:** From within the team, either dedicated admin support or someone who assumes role within the team
- **Technology experts/ data analysts**: You may have access to technology / information analysts in your organisations with access to Electronic Patient Records (EPR) to support in collecting operational data (e.g. referral, volume, demographic data), clinical system information and relevant dashboards.

1.4 Tips on creating the right conditions for improvement and communication

Increase the sense of importance
This clarifies/emphasises why the change is needed. It can involve sharing stories or experiences that illustrate what the problem is or what the future could look like. It helps people to see the need for change and the importance of acting immediately.

Utilise senior sponsors/ leaders
Person or group of people that act as strategic facilitators and can link the work to the wider organisational priorities. These key people can help to maintain momentum, unblock barriers, make sure improvements are aligned strategically, or if necessary, create new strategic imperatives that support the improvements needed.

Create and communicate a clear vision
It is vital to work with the team and other key stakeholders, especially service users, to create a vision of what the improvement should (or could) look like. This helps to ensure that everyone is working towards a common goal.

2. Involving People with Lived Experience

Introduction

Engaging individuals with lived experience in healthcare improvement is essential for designing services that meet their needs, ensuring that improvement work is carried out ‘with’ or ‘by’ those with lived experience, rather than ‘to’, or ‘for’ them’. This guidance provides key principles and a structured approach to meaningfully involve people with lived experience in assessing and improving healthcare services. Your organisation may have a dedicated patient engagement or experience team—consider reaching out to them for support in embedding best practice in your organisation’s context. For this guidance the terminology ‘lived experience representatives’ is used. Within your organisation, you may use different terminology, such as patient, donor, service user, expert by experience, or lived experience expert. Please use the terminology that aligns with your organisation and preferences of those contributing to your project.

Toolkit - 2. Involving People with Lived Experience

2.1 Principles of Meaningful Involvement

- **All participants are equal partners:**
  - Lived experience representatives are included in all stages of a project including initial decision making where possible, ensuring their perspectives shape key decisions and/or future directions of the work.
  - All involved actively work to dismantle any perception of hierarchy or power imbalance between clinical staff and lived experience representatives. This ensures lived experience representatives feel respected, valued, and that their input is not felt to be tokenistic.

- **Ensure flexibility and accessibility:**
  - Offer at least two options for participation (e.g., in-person and virtual, zoom or phone call, dates/times, etc) to accommodate different needs, preferences and schedules.
  - Consider specific communication needs for patient groups (e.g., translation into other languages, visual supports, etc).
  - Provide all necessary resources, such as IT equipment and training, to enable full participation.

- **Inclusivity:**
  - Voices representative of the population you serve, from underserved communities and from diverse backgrounds are included.

- **Communicate clearly:**
  - Use plain language or explain any technical language and provide clear instructions and background information to ensure that all participants understand their role and the objectives of the work you're undertaking.
  - Don't leave lived experience representatives in the dark. Be transparent and honest about any issues (e.g., staff sickness, etc). Communicate any changes and outcomes in a timely manner.

- **Efficiency:**
  - Respect participants' time by keeping sessions concise and focused, and by providing clear agendas and expectations in advance.

- **Feedback:**
  - Create safe environments for debrief/check-ins and options for how to give feedback are given. Group meetings aren't always the most comfortable place to share concerns.
  - Provide regular updates on how is influencing project progress
  - Feedback is given to lived experience representatives on outcomes of the project and how changes may impact lived experience representatives, services and the environment.

- **Reward and recognition for lived experience representatives:**
  - Participants are providing their valuable time and insights - recognition of their skills, time and expertise is very important. Ensure you recognise their efforts in any formal write-up of the work. Any other form of recognition used should be pre-agreed with all participants.

Toolkit - 2. Involving People with Lived Experience

2.2 Approach to Involvement

There are different levels of lived experience engagement which may depend on the type and scale of improvement work. For work that involves understanding of a system and making changes that directly impact those with lived experience, families and carers higher levels of engagement are best practice.

- **Invite someone with lived experience to be part of core team so they're able to contribute from the very beginning of the design of the projects aims and objectives.**
  - How to recruit – contact individuals who have previous experience of all elements of the pathway you are assessing. If you can utilise patient engagement/ experience teams in your Trust for support.
  - Initial engagement - conduct a brief session explaining the project's purpose and seek feedback to clarify the aim and specific changes being considered and how they can contribute their views.

- **Assessing your pathway: involve a representative group of those with lived experience through some or all of these approaches:**
  - Pathway Mapping: Actively involve using a workshop format in mapping out their journey through the system
  - Feedback Sessions: Provide information on existing pathway data or observations, how does this relate to their experience
  - Staff shadowing of patients/donors: Staff shadow user journey to put themselves closer to the mindset of a user experiencing the services, rather than as a staff member. This helps highlight, their experience and can open up dialogue and relationships with lived experience partners.

- **Designing improvements: involve a representative group of those with lived experience through several ways:**
  - Actively Co-Design changes: Hold a workshop or 1:1 interviews with lived experience representatives to brainstorm and refine improvement ideas
  - Advisory Panels: A small panel of representatives can be created to provide ongoing feedback during the design phase. Schedule brief, periodic meetings to review progress
  - Feedback on improvement proposals: Share drafts of proposed improvements with patients/donors for their feedback. Feedback could be gained via surveys, structured or unstructured interviews, etc.
  - Informing patients/donors if a service structure is changing which may or may not impact them. If there is a choice in how donors engage with the changes in the service – make it clear what options they have and how to make their preference known to the service.

- **Measure Impact: Assessing the effectiveness of the implemented improvements. Use an appropriate selection of approaches:**
  - Use short, targeted surveys to gather feedback on specific aspects of the process. Distribute these surveys during routine interactions or at discharge.
  - Assign a designated staff member to gather insights during contacts.
  - Set up a "feedback station" in a common area where donors, families and carers can easily provide input.
  - Gather brief stories (verbal or written) / testimonials about their experiences.
  - Post-Implementation Surveys: Distribute a survey to donors to assess their satisfaction with the changes. Keep the survey concise (5-10 questions) to encourage high completion rates.
  - Focus Groups: Organise a focus group with donors to discuss the impact of the improvements and gather qualitative feedback.
  - Impact Interviews: Conduct short interviews with a few donors to gather detailed feedback on how the changes have affected their experience.

- **Reporting outcomes**
  - Recognise lived experience representatives' contributions to your project in any reporting, sharing and promoting of the work.
  - Ensure a way to provide feedback on the project outcomes to the lived experience representatives who participated in the project is agreed from the project outset.
  - Share the outcomes and learning with your wider donor, family, carer population, e.g., Create a visual resource for a common area (e.g. poster). Leave space for ongoing feedback.
  - Share your work with the healthcare community via the CSH Sustainable Healthcare Resource Library, using the case study template (see page 23)

2.3 Resources and Further Reading

- NHS England's Patient and public participation policy
- National Voices: Principles for Inclusive Involvement
- The King's Fund Patient Involvement Resources

3. How to Map your Pathway and Resource Use - Step by Step Guidance

Introduction

Mapping a healthcare pathway is a critical process for understanding service user journeys, identifying inefficiencies, and optimising resource allocation. This guide provides a step-by-step approach and tools for mapping your LKD assessment pathway while assessing resource use at each stage.

Toolkit - 3. How to Map your Pathway and Resource Use - Step by Step Guidance

3.1 Purpose and Scope

Defining the Objective

- The goal of this pathway mapping is defined as - enhancing sustainable value of the service.
- Key outcomes – Improved donor experience, faster progression through pathway for donors, reduced appointments, better resource utilisation (reduced carbon footprint).

Pathway Boundaries

- The living donor assessment pathway is defined as being from the initial contact with the potential donor up to the pre-operative appointment before surgery.
- Donor group: typical pathway for directed donors, non-directed altruistic donors and donors part of the shared scheme. Excluded: Any additional testing that is not part of standard protocols.

3.2 Steps to Map your Healthcare Pathway

Engaging Key Stakeholders

- Involve relevant healthcare professionals, lived experience representatives, administrators (see pages 10/11)
- Use workshops or individual interviews to gather insights.

Defining your contacts along the pathway

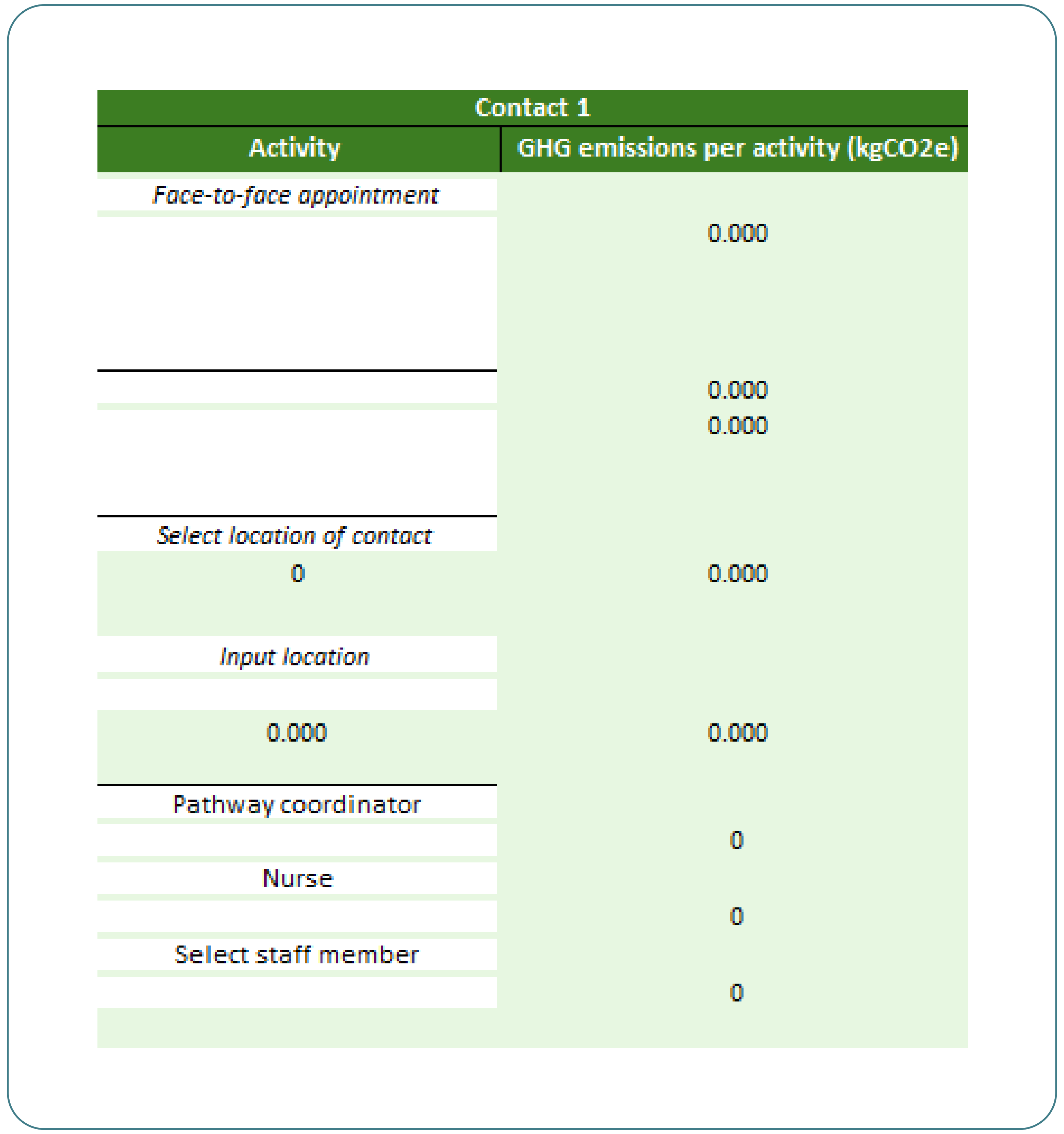
- Use The LKD pathway measurement tool to break down the pathway into sequential contacts and map activities and resource use at each step

Link to create a visual pathway

Visualising the Pathway

- You can use this document to create a visual pathway for reporting or presentations to illustrate the steps and resource allocation of your current pathway and after any changes made

LKD pathway measurement tool



Contact 1	
Activity	GHG emissions per activity (kgCO2e)
Face-to-face appointment	0.000
	0.000
	0.000
Select location of contact	
0	0.000
Input location	
0.000	0.000
Pathway coordinator	
	0
Nurse	
	0
Select staff member	
	0

4. Understanding your donor population

Introduction

Collecting caseload data and understanding your service user group are essential for driving improvements in healthcare processes. This information supports informed decision-making, ensures fair resource allocation, and enhances overall service efficiency. Establish a core dataset that you expect to be able to collect without difficulty and at regular intervals.

Toolkit - 4. Understanding your donor population guidance

4.1 Define the Scope and Objectives

Key questions to answer:

- How many potential donors enter the service?
- How many potential donors complete the pathway?
- What are the demographics (see below) of the donors at each stage?
- Are there any drop-off points, and if so, why?
- Are specific demographic groups underrepresented or overrepresented?

Define Timeframe:

- Analyse data over a defined period (e.g. over a year, January 2024 -December 2024).

4.2 Data Collection and Sources

Data Points to consider collecting:

- Referral/Entry stage: Number of potential donors entering pathway in defined period
- Assessment stage: Number of potential donors assessed in defined period
- Pathway completion: Number of potential donors who entered pathway in defined period who completed treatment / donated, number of dropouts or disengaged potential donors
- Reasons for non-completion (e.g, donor complications, donor withdrew, DCD / Alt. transplant, incompatible, recipient withdrew)

4.3 Demographic Analysis

Demographic Information to Capture:

- Age groups
- Gender
- Ethnicity
- Socioeconomic status (if available)
- Geographic location (postcode or service area)

4.4 Analyse Key Metrics – things to consider

Caseload Volume and Flow:

- Total Caseload: Number of potential donors entering and exiting the pathway.
- Completion Rate: Percentage of donors completing the pathway.
- Dropout Rate: Percentage of potential donors withdrawing / unsuitable before completion.

Demographic Trends:

- Identify if specific groups have higher/lower completion rates.
- Highlight disparities based on age, gender, socioeconomic or ethnic factors. i.e are certain age or ethnic groups underrepresented on the pathway? Are specific demographic groups completing the pathway at a higher or lower rate?

Wait Times and Delays:

- Average waiting time between contacts and delays.
- Length of time to complete the pathway.

4.5 Lived Experience Feedback

- Incorporate qualitative data from lived experience feedback / donor surveys
- Identify any reported barriers and challenges
- What factors contribute to dropouts or withdrawing?

4.6 Use data to develop / influence any proposed changes

Questions to consider?

- How will any change impact demographic groups?
- How will any change impact drop offs? Can we introduce tailored interventions to reduce drop-offs?
- Develop engagement strategies for underserved populations / share learning with transplant patient engagement teams.

4.7 Monitoring and Review

Use data to assess any impact of changes

- Ongoing reviews to assess progress
- Ongoing donor feedback to refine interventions
- Adapt processes to improve donor outcomes

4.8 Additional Considerations

- Ensure compliance with data protection regulations (e.g. GDPR)
- Maintain data collection and address any gaps in record-keeping
- Engage with and validate any relevant findings with stakeholders and staff and gather qualitative insights.

Optimising Your Pathway - High Impact Changes

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Optimising Your Pathway - High Impact Changes

Condensing Appointments

- Streamline the number of appointments by carrying out blood tests, physical health screenings and urine tests in one contact
- Consider which diagnostics (e.g. CT angiography, ultrasounds, ECG) can be completed together*
- Consider bringing consultant, surgical, and independent assessment reviews together*
- Consideration needs to be given to the needs of the donors, if pathways are too inflexible donor drop off/experience potentially outweighs the carbon benefits

**Liaison and alignment with key hospital departments and stakeholders will be crucial to successfully implementing these pathway improvements. This includes close coordination with radiology, cardiology, transplant surgery, and outpatient services to optimise scheduling and minimise delays. Effective stakeholder engagement, collaborative working, and scheduling flexibility are essential to achieving these goals.*

Rationale

Findings from Phase 1 suggest that the highest dropout rate occurs at the initial healthcare screening questionnaire. As most donors proceed to subsequent investigations, condensing appointments is unlikely to lead to significant resource wastage. Consolidating appointments substantially reduces donor travel and time, which, as identified in Phase 1, has the greatest impact on both carbon emissions and donor experience. Streamlining the living donor pathway offers an opportunity to optimise the timing of donation, which may be associated with improved outcomes for recipients.

Potential Outcomes

Faster progression through the pathway for the donor, faster return to pre donation health and function.

Earlier transplantation may shorten the duration of dialysis for recipients, improving health outcomes.

Reduced emissions from donor travel and reduced electricity, gas and water overheads.

Earlier transplantation may shorten the duration of dialysis for recipients, leading to a reduction in the use of this resource-intensive treatment.

Improved donor experience - reduce time donors spend attending appointments, potentially minimising time off work, loss of earnings, and travel-related costs.

Improved staff experience - more efficient scheduling and use of resources provide efficiencies and optimise clinical time.

Optimising Your Pathway - High Impact Changes

Switching from face to face to virtual appointments

Explore whether the initial contact, consultant, and nephrology appointments can be done virtually, offer donors a phone call or virtual appointment via MS Teams, Zoom or other video calling option

**Ensure this is provided as an option only, and face to face options remain, some donors may not have access to the technology needed or face to face may be their preference.*

Rationale

Findings from Phase 1 suggest that some donors may prefer virtual appointments for certain stages of the pathway. Supporting donor choice is key; allowing individuals to select their preferred appointment format can increase engagement and potentially reduce non-attendance (DNAs). Transitioning from face-to-face to virtual appointments also offers environmental benefits by reducing travel-related emissions and resource use within healthcare facilities. Additionally, virtual appointments can lower the time and financial burden on donors, including travel costs and time off work, further enhancing the donor experience.

Potential Outcomes

Faster progression through the pathway for the donor, faster return to health and function.

Earlier transplantation may shorten the duration of dialysis for recipients, improving health outcomes.

Reduced emissions from switching to virtual appointments compared to face to face.

Earlier transplantation may shorten the duration of dialysis for recipients, leading to a reduction in the use of this resource-intensive treatment.

Improved donor experience - enhanced convenience and flexibility, with increased access to appointments. Reduced travel time, costs, and waiting times.

Improved staff experience - greater flexibility in delivering care, and use of resources provide efficiencies and optimise clinical time.

Other potential opportunities for pathway improvement

Other potential opportunities for pathway improvement

As part of Phase 1 of the project, an online workshop was held with participants representing a broad range of roles within Living Kidney Donation (LKD) services, wider healthcare services, and individuals with lived experience. Workshop participants identified factors contributing to variation between services and identified areas where improvements could be made. The additional opportunities for pathway enhancement outlined below came from these collaborative discussions, and are grouped by theme.

Sample Transport and Lab Efficiency

Digressions of processes often arise due to logistical issues such as mislabelled samples, missed transports, which can be caused by inexperience of non-specialist staff. Donor confusion about appointment logistics can also lead to delays. These factors may result in repeated appointments and testing, with delays in logging blood results potentially impacting transplant timelines.

- Review and optimise blood transport processes to prevent delays and repeated testing.
- Provide additional training for non-specialist nurses to handle transports effectively.

Digital Systems

Issues with digital systems were highlighted as hindering local testing capabilities.

Improve IT system interoperability to enhance communication, for example regional renal IT systems that link all regional laboratories through a regional integration engine (RIE).

Reduce Geographic Disparities and Travel Burden

The number of appointments, their locations, and the travel required have the greatest impact on both carbon emissions and donor experience. Given the variability among donors, there is a strong case for offering local testing options and flexible choices for consultations to reduce the frequency of contact. Equity of access was a key theme, particularly for donors facing financial constraints, highlighting the importance of localised services. Donors are more likely to attend appointments that are closer to home, presenting a clear opportunity to reduce non-attendance (DNAs).

- Explore mobile transplant teams for better access where feasible.
- Consider testing in local centres/ primary care. Acknowledging logistical challenges as may increase pressures.

Donor Engagement and Coordination

Donor engagement is critical, and services must prioritise equity, both at the point of entry into the pathway and throughout the entire donation journey.

- Foster collaboration between donor and recipient teams to increase equity of those entering the pathway and to reduce pathway dropouts.

Streamline Pathway and Referral Processes

There are significant variations between centres in both the types of investigations conducted and how they are delivered.

- Explore how to create quicker pathways for specialty referrals.
- Investigate alternatives to requiring final cross-match visits 2-4 weeks before surgery.

Case Study Template

You are strongly encouraged to write up and share any work you have completed to improve your pathway using these tools. Below is a link to a case study template you can download and use to report your work and outcomes. Several sections have been pre-populated to get you started, you may choose to use this or change or adapt the wording.

Below you will find case study report guidance to help you complete all sections.

Once you have completed your report, please share with colleagues on our 'Networks Resource Libary'. Sharing your hard work and encouraging good practice will play an important role in supporting others to replicate your project or apply your methods and learning to similar projects.

Links

Living Kidney Donor case study template

Case study template guidance

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