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# Developing a patient experience survey for liver transplant care

# Background

On behalf of the British Liver Transplant Group, Picker developed a liver transplant patient experience survey to help transplant centres understand how people experienced their care services and where there might be room for improvement.

Before this, there was no robust measure to understand people's experiences of liver transplantation in the UK.

Funding was provided by the British Liver Trust alongside charitable funding from the seven UK adult liver transplant centres who helped to test the new survey as part of the pilot work.



# What we did

We conducted a literature review and patient interviews which revealed the following themes were important in the provision of liver transplant care:

- Information and communication
- Treatment and care
- Post-transplant support
- Family support and involvement
- Care coordination and continuity

These themes, alongside Pickers principles of person centred care, informed the development of the draft questionnaire, which covered:

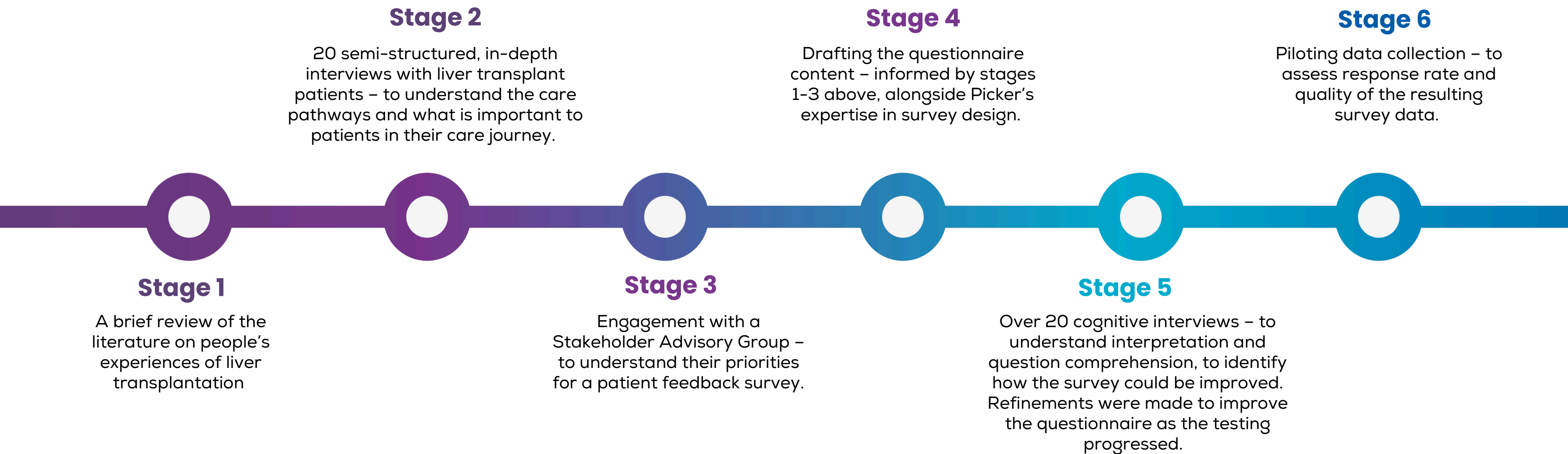
- Pre-transplant care and communication
- Experiences of care during the hospital stay
- The transplant procedure, including communication about expectations
- Post-transplant care, including information, ongoing support and quality of life
- Demographic questions such as gender, country of residence and ethnicity

The survey was then cognitively tested, resulting in some changes to improve people's understanding and interpretation.



# What we did

We followed our tried and tested survey development approach which involved the following stages:





## What we found

**The survey was piloted with eligible patients who had received a liver transplant between three months and three years ago at one of seven transplant centres in the UK.**

People were invited to complete the questionnaire via post.

2,006 patients were invited to take part, and up to two reminders were sent to non-responders. **1,198** recent liver transplant patients responded, yielding a response rate of **60%**.

The survey functioned well, as demonstrated by the overall response rate. Furthermore, data for individual questions were reviewed and showed minimal missing data (unanswered questions) and a low dropout rate.

67%

of respondents were on the waiting list **less than 6 months**

79%

of respondents said a **member of staff definitely kept family informed about the progress of their operation**



**86%**

of respondents reported always having confidence and trust in the health and care staff treating them

**79%**

of respondents reported that a member of staff answered their questions about their operation in a way they could understand



**89%**

**of respondents** said that after leaving hospital they felt their condition was monitored adequately by their transplant team



**40%**

**of respondents** said they were offered timely support from a counsellor, psychological or other support services



# What are the next steps?

The liver transplant survey is available to liver transplant centres to enable them to collect actionable data to understand patient care experiences and identify areas for improvement.

To request access to the survey, please email [licensing@pickereurope.ac.uk](mailto:licensing@pickereurope.ac.uk). However, please note that the survey should be reviewed and updated prior to use, as it was developed before the Covid-19 pandemic and there may be differences in the way liver transplant services are now delivered. Picker can support with reviewing and adapting – please contact us for further information.





## **Amy Tallett, Head of Research:**

"The liver transplant patient experience survey provides an important opportunity to better understand the experiences of people who have undergone liver transplantation. It can be used to gain insights to support ongoing efforts to improve care, enhance communication, and ensure services continue to meet the needs of patients, so that care is truly person centred."



## Acknowledgements

We would like to thank the patients who took the time to speak with us and share their experiences of care.

We are grateful to the British Liver Transplant Group, British Liver Trust and the transplant centres (Royal Free Hospital; Royal Infirmary of Edinburgh; Queen Elizabeth Hospital Birmingham; Addenbrookes Hospital; King's College Hospital; St James University Hospital; Freeman Hospital) who participated in the pilot study.



In addition, we would like to thank the Advisory Group members who provided expert advice and guidance throughout the development of the survey.



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