



**Influence,
inspire,
empower.**

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Foreword

In 2020, Picker celebrates 20 years of dedication to developing and promoting a patient centred approach to healthcare, as first advocated by our founders Harvey and Jean Picker.

Now, as then, we continue to strive for further improvements in practice to ensure staff and patients remain at the forefront of healthcare. This past year has provided its own challenges, which our team has risen to admirably in the continued pursuit of excellence and expansion into multiple new areas.

Most notably, in 2019 we were awarded the contract for the National Cancer Patient Experience Survey (NCPES) and the new Under 16s Cancer Patient Experience Survey (U16 CPES). Working alongside the U16 CPES advisory group, we're delivering the insight needed to transform the experiences of children with cancer - it's a privilege to be instrumental in understanding the patient experience for cancer care from birth right through to adulthood.

We have also maintained our collaboration with a wide range of organisations doing vital work. Our ongoing partnerships include a number of individual NHS trusts, NHS England and NHS improvement (NHSEI), pharmaceuticals, charities, government bodies, universities, care homes and royal colleges. At Picker we believe that fostering this breadth in our partnerships is key to influencing healthcare policy and promoting and improving patient experience.

On page 23 you will learn about our latest work with the Welsh government, a relationship we're proud to continue developing as a trusted partner. We have also

increased our reach globally: in the Netherlands, the Picker Principles operate as a framework to benchmark research against other regions and countries, whilst our global work with the Lymphoma Coalition has gathered approximately 10,000 responses. Person centred care should not be restricted by geography, and our work seeks to advocate for excellence in person centred care worldwide.

Moving into 2020, our 20th anniversary year brought with it the unprecedented global strain of the Covid-19 pandemic. Now, more than ever, it is vital that we continue our mission to empower organisations worldwide in the delivery of person centred care. In both health and social care wellbeing for people, for staff and for carers is paramount. Our commitment to wellbeing extends to our own hardworking team at Picker. I'd like to take this opportunity to thank them all for seamlessly working from home and for the dedication and focus they have shown in continuing their excellent work this year.

I look forward to sharing our 2020 work in next year's report, and as we come out of the pandemic we'll be working with organisations to understand people's experiences of care well into the future.

Professor Aileen Clarke
Chair of the Board of Trustees

Introduction

For the last twenty years, Picker and our dedicated team have worked to promote the concept of person centred care. As we celebrate our 20th birthday, we can reflect with pride on our achievements along the way.

Picker has undoubtedly played an important part in the increased recognition of person centred care in the UK and internationally. We've been particularly successful in influencing the adoption and use of large-scale survey programmes, collecting feedback to evaluate the quality of care through the patients' eyes. We've also worked with providers and commissioners to help them create and sustain improvements in the care experiences of their patients and staff, and with charities, academic institutions, and others to advance our field and to better understand the views and priorities of a wide range of groups.

This year, we have continued this important work – and I'm delighted to introduce Picker's latest Impact Report, which highlights some of our key projects and successes during 2019/20.

National programmes evaluating the experiences of large groups of patients and staff remain important to the work that we do, and we are delighted to continue to lead a number of such programmes in England. These include the colossal NHS Staff Survey as well as our ongoing work with the Care Quality Commission (CQC). This year, we are particularly pleased to have started work on two programmes – both commissioned by NHSEI relating to the experiences of adults and of children and young people with cancer: see page 27 for more details.

As well as delivering high quality services, we always strive to innovate and improve to offer the highest quality insight and support to our clients. This year we have made significant steps in working with our partners to launch a new online research platform and to use advanced artificial intelligence techniques to help clients make sense of high-volume narrative feedback. This represents a continued evolution of the work we can do, and further development of our digital offer is planned.

Of course, the last few months of the year brought a new challenge that has affected individuals and care systems across the world. By March 2020 Covid-19 had already had an impact in several ways, including the cancellation or suspension of national projects as well as the individual and organisational pressures of a national lockdown in the UK. Thanks to existing contingency plans, we were able to react quickly and move our colleagues to home working with minimal disruption – and I couldn't be more proud of the resilience, adaptability, and commitment that the whole team has shown in responding to the situation.

Investigating the impact of Covid-19 on people's experiences of care will, of course, be part of our agenda for 2020/21. Looking ahead, we're also excited to begin work on a number of new projects that will allow us to continue to influence, inspire, and empower in pursuit of the highest quality person centred care for all, always. Examples of our future programme are provided on page 28 – and we look forward to reporting on these in the year to come.

In the meantime, I hope you will enjoy reading this report and learning about our work in 2019/20. If there's anything you'd like to know more about – or if you'd like our help with measuring, understanding, and improving people's experiences – please don't hesitate to get in touch.

Chris Graham
CEO



Our values

Our four core values underpin everything that we do, reflecting what we believe in and how we behave:

Excellence

Maintaining the quality and consistency of our work is our highest priority. We are not willing to accept the status quo and continuously look for new ways to understand, measure and improve the quality of health and social care.

Integrity

We ensure our independence using the best possible evidence to drive and support our decision making, our statements and our activities. Our behaviours match our words and we are accountable for all that we do. We only engage in activity which furthers our charitable aims.

Valuing diversity

We recognise all people as equals, valuing individual worth and diversity. Ideas and contributions are judged on their merit not their source.

Collaboration

We encourage ideas and knowledge to be shared freely. We believe that lasting change cannot be delivered in isolation and actively seek partnership opportunities to achieve greater impact.

Our mission

We are here to:

Influence
Inspire
Empower

Our vision

The highest quality
person centred
care for all,
always.

Picker Principles

Developed from original research, our Picker Principles of Person Centred Care continue to underpin our work globally. Their purpose? To outline the things that matter most to all those who use care services, and to define the key elements that should remain non-negotiable in the delivery of care.

Picker Principles of Person Centred Care:



Fast access to reliable healthcare advice



Effective treatment delivered by trusted professionals



Continuity of care and smooth transitions



Involvement and support for family and carers



Clear information, communication, and support for self-care



Involvement in decisions and respect for preferences



Emotional support, empathy and respect



Attention to physical and environmental needs

Groundbreaking research

Our eight key Principles have their origins in Picker's research in the USA, starting in 1987. By 1993 the Principles were firmly established and have since been used internationally in our commitment to excellence in care provision.

Then, as now, the Picker Principles influence conversations around person centred care worldwide. What was groundbreaking research at the time now holds significant reach, embodying our belief that everybody deserves high quality care that addresses their own individual preferences and needs.

The Principles in action

The Picker Principles are internationally recognised as a framework to facilitate the delivery of consistent, high quality care. We help individuals and organisations to implement these by providing improvement services and advocating for the continued placement of people at the heart of care provision.

The Principles are key to our own research, too, and we use them as markers for us to collate evidence - in turn enabling us to influence policy and practice for the better.

Principles into practice

We are committed to what we do: from coordinating groundbreaking research to working alongside healthcare commissioners to improving service delivery.

Our team of project managers, insight experts, analysts and researchers work in collaboration with world-leading academic and research institutions to deliver projects in line with our mission and vision:

- **Specialist research and analysis**
We design and deliver original health and social care research, creating evidence to advance thinking around person centred care.
- **Policy papers and trend analysis**
We work with policy makers to put person centred care at the core of health and social care systems.
- **Consultancy**
We work directly with leadership teams within organisations to help them understand the needs of their staff and service-users. We then support the introduction of new practices to improve staff and patient experience.
- **Insight and quality improvement services**
From board facilitation to workshops and presentations, we can help organisations to improve the quality of care they provide.

- **National Programmes**
Picker is both a coordination centre and an approved contractor for the NHS national staff and patient survey programmes, gathering and interpreting vital feedback.
- **Patient, staff and user experience workshops**
Attendees learn to make the most of their experience data, and share best practice with their counterparts nationwide.
- **Toolkits**
Downloadable from our website, Picker toolkits can be used by organisations to understand their patients' views and improve their experiences.
- **Always Events® framework**
Always Events are aspects of the patient experience that must be performed for every individual, every time. We have produced a framework for this in collaboration with the Institute for Healthcare Improvement.



Celebrating 20 years

2020 marks the 20th anniversary of Picker Institute Europe as a charity: that's two decades of putting people at the heart of care. Our commitment to providing person centred care started with the personal experiences of our founders, Harvey and Jean Picker.

In 1986, Jean was undergoing treatment for a long-term condition. Whilst the USA's healthcare system was technologically and scientifically advanced, Harvey and Jean did not find it to be sensitive to the individual needs and preferences of its patients. This needed to change.

Later that year, Harvey and Jean founded The Picker Institute, a non-profit organisation dedicated to developing and promoting a person centred approach to healthcare. In 1987, the Institute began developing the eight Picker Principles of Person Centred Care – the full story of their

groundbreaking development was later recorded in "Through the Patient's Eyes" (1993).

Picker now celebrates 20 years of advancing person centred care. Our innovative work continues, from partnering with world-leading pharmaceutical organisations and healthcare providers to working with governments, universities and charities.



2002

Picker named as the NHS regulator's partner of choice to design and establish the NHS National Survey Programme, the first ever national survey programme for patient experience.

Picker establishes a quality improvement service, dedicated to supporting organisations to act on their user experience data to improve care quality.

2011

Picker is the Department of Health's partner of choice to run the NHS National Staff Survey, among the largest workforce surveys in Europe.

Picker creates a patient-reported experience measure for children and young people. This wins an NHS Department of Health award and is taken to the international stage with uptake in the USA and Australia.

2015

The World Health Organisation (WHO) evaluates the quality of care for adults with psychosocial and intellectual disability in the WHO region, with Picker contributing analysis and reporting.

2017

Picker's national Children and Young People's experience survey secures a regular position on the CQC evaluation roster.

2019

Picker signs a new contract to manage the national cancer patient experience survey (NCPES) for NHS England.

Quality, Safety, and Outcomes of Health and Social Care Policy Research Unit launched as a collaboration between Picker, the Universities of Kent and Oxford, London School of Hygiene and Tropical Medicine, and Hull-York Medical School.

2003

Picker develops and coordinates the first ever survey of service users' experience of mental health services in England.

2014

Picker collaborates with the Institute for Healthcare Improvement, bringing the Always Events® improvement programme to European health and social care jurisdictions.

Picker works with the CQC to run the first national Children and Young People's experiences survey across the NHS in a decade.

2016

Launch of the first ever national patient experience evaluation in Ireland, produced by Ireland's Health Information and Quality Authority (HIQA), Health Service Executive (HSE), and Department of Health with support from Picker.

2018

Publication of 2015 research on disability in the WHO region.

Picker signs a four year contract with Mind to run their "Big Mental Health Survey".

2020

Picker signs a contract to design and run the Under 16s Cancer Patient Experience Survey.



2000

Picker (then called Picker Institute Europe) was formally created and based in the UK.



Our global impact...

Research, analysis and evaluation programmes throughout the world.



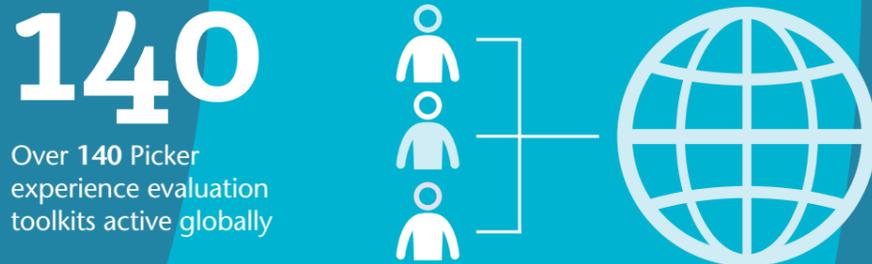
Let's look at the numbers

We partnered with: AbbVie Ltd; CQC; East Lancashire Hospitals NHS Trust; HIQA; Helen & Douglas House; Hull-York Medical School; London School of Hygiene and Tropical Medicine; Lymphoma Coalition; Netherlands Federation of University Medical Centres; NHSEI; Oxford Brookes University; Oxford University Hospitals NHS Foundation Trust; Royal College of Paediatrics and Child Health (RCPCH); Welsh Government; Welsh National Collaborative Commissioning Unit; University of Kent and University of Oxford.



Influence

Influence policy and practice so that health and social care systems are always centred around people's needs and preferences.





Picker surveys provide a robust measure for patient experience in the Netherlands

The Netherlands Federation of University Medical Centres (NFU) wanted to develop surveys that could provide valid, reliable patient experience data suitable for comparing results across hospitals. They invited Picker to speak at Erasmus University Medical Centre (UMC) Rotterdam about the Picker Principles of Person Centred Care and patient experience evaluation.

The NFU wanted to introduce internationally recognised surveys, which they could adapt for use within their own hospitals. Working alongside the NFU, Picker delivered three surveys working on already-successful models: inpatients, outpatients (both adults and children/young people) and social care surveys. With additional input from patient groups, Erasmus UMC developed the surveys into their own Patient Experience Measure (PEM). These were then piloted at Erasmus UMC before being introduced to a further seven university hospitals later in the year.

This has allowed the NFU continuously to improve the care and services within their hospitals: results of the questionnaires facilitate internal benchmarking between teams, departments, and themes, and perform external benchmarking with other UMCs as well as with other hospitals worldwide.

Looking forward

Following on from this initial success, Picker has helped the NFU expand their patient experience surveys into emergency care settings. The patient experience work carried out with the NFU has spread to other hospitals in the Netherlands, and now two further hospital groups - consisting of 25 hospitals - are piloting the surveys for their patients.

In continued work across the two countries, Picker's research in the UK into sickle cell disease has been adopted as the basis for research into the care experience of this group within the Netherlands.

There is further potential for international benchmarking of experience between the Netherlands and the UK, as well as more widely across the international medical community.



Understanding patient experiences of urgent and emergency care

Picker coordinates the Urgent and Emergency Care (UEC) Survey, part of the CQC-funded NHS Patient Survey Programme (NPSP). This project is vital for understanding and measuring the experiences of people in major Accident & Emergency departments (Type 1) as well as minor injury units and urgent care/treatment centres (Type 3).

This was the ninth iteration of the survey, and the first to collect data and report on Type 1 and Type 3 departments separately, enabling a better understanding of people's experiences of the two (very different) services. Out of 132 trusts that took part, more than half worked with Picker as their chosen contractor to carry out the survey.

Challenges

It was vital that both the Type 1 and Type 3 questionnaires were fit for purpose. We addressed this need by:

- Meeting with the survey advisory group to discuss the previous years' survey data and to address key challenges.
- Consulting with 50 trusts over email and completing in-depth interviews with two, to better understand the set-up and provision of Type 3 departments as distinct from Type 1.
- Analysing Hospital Episodes Statistics (HES) data on Type 3 attendances to better understand the probable number of trusts that would be eligible to submit a Type 3 sample.
- Conducting cognitive interviews with people who had recently used UEC services to ensure they were interpreting and understanding the questions as expected.

Actions

Following the extensive development work we carried out, several changes were implemented for the new 'Urgent and Emergency Care Survey'. Most notably:

- Distinct questionnaires and covering letters were designed, tested, and implemented for both Type 1 and Type 3 services.
- The sample size was increased, and the sampling month was extended for Type 3 services to account for the expected low numbers of eligible patients at trust-level.

Impact

The development work that we carried out proved effective. For Type 1 departments, over 42,000 people responded, and over 7,000 responded for Type 3 departments. A significant increase in response rates for both.

On a national level, we produced two open source files for the two service types, each with tables presented for each question and an indication of any significant changes from the previous UEC Survey.

With the structure of UEC services undergoing vast changes over the years, and with mounting pressure on staff due to an increase in the number of attendances every year, these outputs highlight essential information for policymakers and regulators on what is going well and what areas need attention.

Going Forward

Following the Covid-19 pandemic, in the next iteration of the survey we will be working on understanding how UEC services and people's experiences of these services have changed. The results of this work will influence the content of the questionnaire to ensure we capture vital information regarding care during the pandemic.



Fast access to reliable healthcare advice



Effective treatment delivered by trusted professionals

Amplifying employee voices for East Lancashire Hospitals NHS Trust

East Lancashire Hospitals NHS Trust (ELHT) is a healthcare provider treating over half a million patients a year in the North West. Back in 2013 they were investigated as part of the Keogh Review and were categorised as an organisation in “special measures”. Morale amongst staff consequently hit rock bottom, against a backdrop of negative media articles.

Working with Picker and using the Staff Friends and Family Test, ELHT wanted to offer an environment for all staff members to speak up about their concerns in order to establish the cultural change required to turn things around.

Challenges

- A communication gap between board and ward, negatively impacting staff morale.
- Feedback highlighted the challenges facing frontline staff were not understood.
- ELHT needed to create freedom for staff to speak up and feel valued in their work.

Actions

ELHT invested in a dedicated staff engagement team, who used the survey as a springboard to reach out to staff and identify key enablers. Along with the strategy, an annual employee engagement action plan was monitored by the employee engagement sponsor group, chaired by the Chief Executive.

Picker also ran workshops with the ELHT teams following each release of the NHS Staff Survey, providing staff with the space to discuss and reflect on the results. Based on staff feedback, numerous interventions have been introduced, including:

- Employee of the month and ‘Engaging Managers’ programmes.
- Mental Health First Aid training and mediation for staff.
- A ‘Back to the floor’ programme where each of their directors on a monthly basis walk in the shoes of the staff to demonstrate visible leadership.
- Staff engagement zones on each site, visibly promoting information, feedback and critical communications.

Impact

ELHT have seen significant improvement in their overall engagement score, a key metric of staff motivation. In the NHS Staff Survey 2019, satisfaction responses were better than average for eight out of ten key themes.

In February 2019, ELHT’s CQC rating had risen to ‘good’ - and they’re continuing to work to improve further.

Going Forward

The project continues to improve the experiences of staff and patients at ELHT. They hope that with the actions they are putting in place, they will soon progress to a CQC rating of outstanding.

“With Picker’s guidance, we were able to use the insights from the NHS Staff Survey and the Staff Friends and Family Test to continually develop our staff programme and create the sense of belonging we want for our staff.”

Lee Barnes
Associate Director Staff Wellbeing Engagement, East Lancashire Hospitals NHS Trust.



Clear information, communication, and support for self-care



Emotional support, empathy and respect



Growing our network

Pharmaceutical partners

Among our projects on behalf of pharmaceutical partners in 2019, we conducted research with AbbVie Ltd, gathering the experiences of dermatology patients living with moderate to severe skin conditions (atopic dermatitis, hidradenitis suppurativa, and psoriasis). Our lead researchers publicised their findings at a shared decision making showcase at the Houses of Parliament, as well as releasing a video, booklet and social media campaign.

Further pharmaceutical partnerships were formed in 2019, including one as a direct result of a recommendation from the CEO of the Sickle Cell Society at an international symposium. Our work with pharmaceutical partners is wide-ranging, including the design and development of specialised courses, training teams in the evaluation of patient experience.

Academic research

In a collaboration led by Oxford Brookes University, with input from Oxford University Hospitals NHS Foundation Trust, Picker are sitting on an expert committee supporting

the development of a new Patient Reported Experience Measure. This new measure specifically looks at diabetes-related care during inpatient stays, and we are contributing our expertise in the design of survey questions as well as advising on cognitive interviewing strategy.

International reach

Pushing for global developments in person centred care remains a focus for Picker. In 2019 we supported Ireland's first-ever National Maternity Experience Survey, providing an expert review of the questions as well as consultancy on the sampling and reporting of the programme. The results - published in October 2020 - demonstrated that 85% of participants had either a 'good' or a 'very good' experience of maternity care in Ireland.

We have also sought to support effective and sustainable changes elsewhere, including our implementation of experience surveys in university medical centres (see page 15). In early 2020, our global survey of patients and caregivers for the Lymphoma Coalition (see page 10 and 11) gathered over 10,000 responses, across five continents.

Inspire

Inspire the delivery of the highest quality person centred care, developing tools and services that enable people's experiences to be better understood.





Continued support for Welsh healthcare services

Picker, National Collaborative Commissioning Unit Wales (NCCU) and the Welsh government have been collaborating to support the development of healthcare insight and policy in Wales since 2017 when Picker helped to redesign the experience-based elements of the Welsh CAREMORE Commissioning framework. Since then, person centred care has been gaining momentum across the Welsh healthcare system.

In 2018, Picker conducted the first national perceptions study into awareness of and access to urgent care across Wales. We presented the results of this programme to the Welsh government, establishing the need for additional funding during the winter period and a clear communications strategy for public engagement. Since then, Picker's work with NHS Wales and the Welsh government has continued to prioritise the embedding of personal experiences and perceptions into system-level changes.

Working alongside the NCCU and Welsh Ambulance Service NHS Trust to understand public perceptions and service user assessment of the proposed changes to their amber call categorisation, Picker identified:

- what matters most to citizens when calling 999; and
- what drives public choice to use 999 over other urgent care services.

The insights from the study were then used to drive improvements in conveyance and experience outcomes.

During 2019, we have continued to collaborate with the Welsh health and care system:

- Picker and NHS Wales have engaged with emergency department staff to conduct the first systematic staff experience evaluation across all thirteen Type 1 emergency departments in Wales. The insights are being used to improve staff experience through local and national initiatives.
- Picker's work inspired the NCCU to use our public perception and experience model to support their Mental Health Urgent Care Access review. The results will inform the Welsh Government's forward priorities around access to mental health support during crisis.

"Picker is an essential partner who provide independent, expert advice supporting us to keep people's experiences at the centre of policy and practice in NHS Wales."

Julian Baker

Director of National Collaborative Commissioning, NHS Wales.

Shaping future services at Helen & Douglas House

Helen & Douglas House provide hospice and palliative care to babies, children, and young people in Oxfordshire and surrounding areas. They wanted to explore the needs of service users, families and staff, to ensure their care provision matched the needs of these groups. Picker were commissioned to explore the following questions:

- What do users think about the environment in which care is delivered?
- How accessible and available are the services offered by Helen & Douglas House, and how well are user needs being met?

- How would users, staff and stakeholders like to see services developed, and what are their suggested changes to support future needs?

Based on the responses of service users and wider stakeholders, the following areas of desired improvement were highlighted:

- Environment: More specialised equipment such as beds, designated areas for staff, zoning of age-appropriate areas for children, better designed outdoor space, and more clinical space (e.g. medication storage).
- Accessibility and availability of services: Making it easier to drop off or pick up children, more sensory activities to be available, further support for the wider family, and continued services for young people over 18.



“Working with Picker on this research has ensured that we develop our services and facilities in the most appropriate way for our visiting families. We’ve been able to prioritise some quick wins and put longer-term plans in place to ensure the more expensive suggestions can be funded. We’re excited to see the difference the changes make to the lives of our families.”

Andrea Lambert

Director of Clinical Services,
Helen & Douglas House.



When asked what they believe to be the priority area for investment, the majority of staff and stakeholders suggested:

- increased staffing, to help facilitate key aspects of care: more beds to increase respite flexibility and to cope with emergencies,
- therapeutic support for families; and
- more physiotherapy and occupational therapy input.

Challenges

Staff and associated stakeholders acknowledged recruitment difficulties, and expressed a desire for support in this as well as additional resources - for instance the opportunity to liaise further with Oxford University Hospitals when specialist care or equipment is required.

Other challenges raised included space and financial restrictions, as well as the service requirements of children with life-limiting conditions living longer due to advances in medical care.

Actions

Responding to the above, Helen & Douglas House has implemented the following changes, including:

- A new ‘teen space’ to facilitate age appropriate ‘zoning’ and help teenage visitors feel more comfortable.
- More autonomy for children and families during their stay. This includes selecting their favourite activities (from a visit to the ice-cream parlour to

a spa day, or an artwork project) and the option to extend booked stays by including Sunday night.

- An updated booking process, aiming to reduce the frequency and impact of cancellations.
- A recruitment drive for nurses and care team members at all levels.

Planned Changes and Impact

As more budget becomes available, Helen & Douglas House intend to:

- Refurbish the spa room for added comfort.
- Incorporate more private areas for families, by refurbishing/amending existing areas and redesigning the garden for 2021 - the latter project will involve consulting with the children and their families.

These planned changes, among others, will enable more families to benefit from the support of Helen & Douglas House. The increased flexibility of drop off will allow families to take breaks with their other children, make more use of the facilities when at the House and most importantly, achieve the respite and family time they need.



Involvement and support for family and carers



Attention to physical and environmental needs

National programmes

Our work with the CQC is established and wide-ranging: we compile, run, and analyse NHS Patient Surveys, as well as handle and disseminate the data gathered - our additional role as a CQC approved contractor makes us uniquely placed to derive the best from these insights.

Surveys for the CQC

Children and Young People's Patient Experience Survey

- Gauging and monitoring the experiences of children and young people admitted to hospital as inpatient or day cases.

Adult Inpatient Survey

- Deriving insight from the feedback of adults admitted to hospital as inpatients.

Urgent and Emergency Care Survey

- Understanding the experiences of adults who received care from an emergency department or an urgent care centre.

Maternity Survey

- Gathering the experiences of women across the maternity pathway.

Community Mental Health Survey

- Surveying individuals who received care in the community for a mental health condition.



Surveys for NHS England and NHS Improvement

NHS Staff Survey

The NHS Staff Survey is carried out by Picker's Survey Coordination Centre for NHSEI. Approximately 1.1 million surveys are sent out annually to NHS staff. In our role as a contractor for the survey, we run workshops for key stakeholders to ensure the survey findings are actioned - we assist participating organisations with staff wellbeing and retention.

National Cancer Patient Experience Survey

In May 2019 Picker was awarded a three-year contract to work alongside NHSEI in delivering the National Cancer Patient Experience Survey. First undertaken in 2010, this survey encompasses the experience of thousands of adult cancer patients across England and is a key resource for healthcare professionals looking to improve their services.

The Under 16s Cancer Patient Experience Survey

In 2019, we were awarded the contract to develop and run a new programme aiming to understand the experiences of cancer care among children under the age of 16 and their parents.

The survey programme has been developed with extensive input from young patients, parents, clinicians and charity representatives, and we are looking forward to launching the first round of fieldwork in 2021.

The results of the survey will be used to help commissioners, providers and national policymakers to identify priority areas for improvement in children's cancer services.

Upcoming projects

Responses to care during the Covid-19 pandemic

We are working with collaborators from Universities of Oxford and Kent amongst others, as part of our Quality Safety and Outcomes Policy Research Unit (QSO PRU) – funded for five years by the National Institute for Health Research.

The unprecedented challenges presented by Covid-19 have led to rapid changes in how care is delivered – including a significant increase in the volume of care delivered remotely through online means. We are analysing online social media data to better understand how people are talking about health and care delivery during the pandemic. These findings will be used by healthcare professionals, policy makers, and patient charities to ensure patients are supported throughout and beyond the current pandemic - without compromising quality of care.

Collaboration with The International Kidney Cancer Coalition (IKCC) Survey on experiences of kidney cancer care

Picker are collaborating with IKCC, an independent international network of specialised patient organisations, to conduct a survey looking into experiences of kidney cancer care. We are developing and delivering IKCC's bi-annual survey, evaluating experiences of service users and their families worldwide.

The NHS Long-Term Plan

The NHS Long-Term Plan (published January 2019) signalled the development of a new Local Integration Index, which Picker will be instrumental in developing. In collaboration with the King's Fund, we are working on behalf of NHSEI to explore how integrated care could be understood locally. As part of this work we will be producing a guide for Integrated Care Systems on how to understand integration from a user perspective.

Understanding Urgent Care Behaviours in London

Due to the public health priority to avoid crowding in emergency departments and urgent treatment centres as a result of Covid-19, Picker will be working on behalf of Healthy London Partnership and NHSEI to host an online survey that explores people's health behaviours. In particular, we will assess why people present at emergency departments and urgent treatment centres, and what steps were taken beforehand.

Adverse Medical Incidents and Outcomes

Picker will be supporting a team at London School of Hygiene and Tropical Medicine on a project to investigate people's experiences of medical harm. The study will look at how common it is for people to experience physical or psychological harm due to failures in healthcare, and will investigate people's decision-making processes about how and whether to complain or seek legal redress. This work will ensure that future NHS interventions address aspects of patients' and families' experiences that are most important to them, and are thus most likely to promote the best long-term outcomes in the circumstances.

Empower

Empower those working in health and social care to improve experiences by effectively measuring and acting upon people's feedback.



Driving improvements in paediatric diabetes care

Working with the Royal College of Paediatrics and Child Health (RCPCH), we sought to develop and assess the validity of a new paediatric Patient Reported Experience Measure (PREM) for diabetes care, to be used in the National Paediatric Diabetes Audit (NPDA).

Challenges

As well as the lack of specific diabetes care surveys for children and young people, the project also needed to overcome the following:

- Concerns around the existing patient experience survey, and whether the questions were designed with children and young people in mind.
- Whom to speak to when assessing paediatric care: parents, children or both? At Picker, we know it's essential to hear from both, and decided to adapt the questions for each of these groups.

Actions

Five focus groups were conducted with 25 participating children and young people with diabetes and their parents to explore recent diabetes care experiences. PREM questions were drafted with clinical insight from an advisory group, including paediatric endocrinologists. The PREM was cognitively tested

with eight patients and eight parents to make sure that the language was appropriate, and the questions were interpreted as intended. This methodology was then rolled out across 12 paediatric diabetes clinics across England and Wales.

Respondents accessed the survey either online or within the clinical setting. PREM validity was crucial, as the data needed to be actionable. We explored patterns in the pilot data, question-by-question, to ensure this.

Impact

After removing questions which were found to be working poorly in the pilot, the newly-improved PREM is now being implemented with a set of scoring metrics that will allow diabetes care providers to understand the needs of their young patients and action improvements. The surveys will also prove useful for benchmarking against other NHS Trusts.



Clear information, communication, and support for self-care



Involvement in decisions and respect for preferences



“Having a new PREM has enabled us to understand where children with diabetes need more support with self-care and any gaps in current service provision, both locally and nationally.”

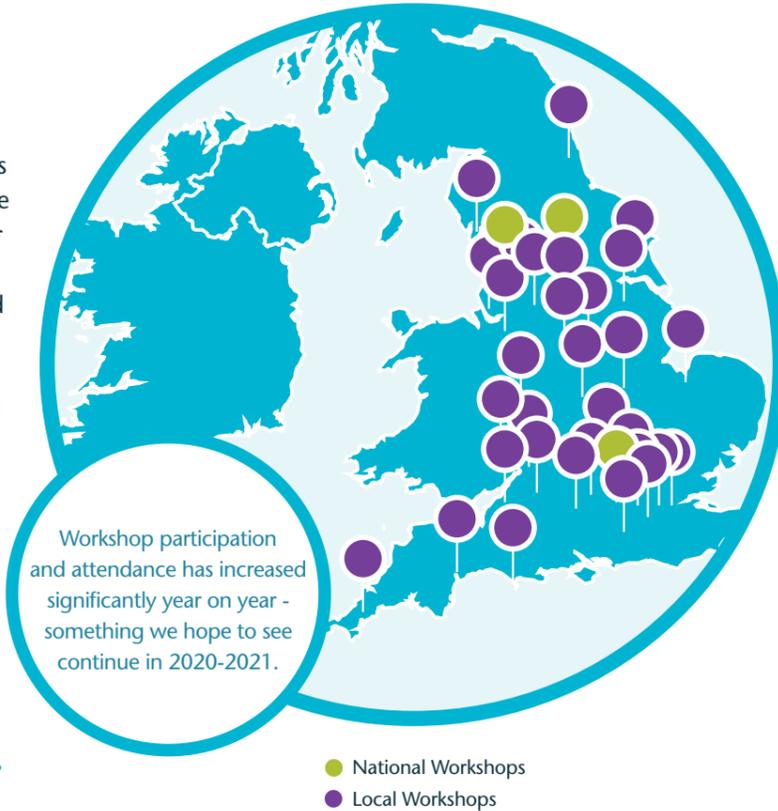
Holly Robinson
NPDA Manager, RCPCH



National and local workshops

We understand that our survey findings are only as good as the actions taken to address them, and we work tirelessly to support NHS trusts in utilising their data to make improvements. We support trusts at a national and local level by providing engaging and actionable workshops, inviting influential guest speakers at the forefront of their respective fields. Attendees welcome the space to share learnings and experiences with their counterparts across the UK.

- **9 national workshops with 227 attendees**
- **97 local workshops attended by 1,750+**
- **17 workshops moved online.**



“Thank you so much for hosting the Teams meeting workshop yesterday. It was extremely interesting and informative. I am always pleasantly surprised how 3.5 hours can pass so easily on a video call, so hats off to the organisers”

“Thank you for the really helpful workshops. You really brought the results to life and engaged the teams in finding solutions”

Lisa Walker @lisa_annWalker - 24 Oct 2019
 Amazing day representing @enherts at the CYP Picker workshop. Loads of ideas about how we can engage our young people in our services @cazdilks #PatientExperience #Pickerworkshops

Anette @AnetteGrahns - 28 Feb 2019
 Back from a good day in Manchester, meeting interesting NHS colleagues, sharing best practice around staff engagement and the NHS Staff Survey. Thanks all, incl the Picker Team for hosting! #pickerworkshops #nss19 @RDEhospitals

Responses to Covid-19

As with all organisations, the Covid-19 pandemic has affected our activities and decision-making, with the virus control measures introduced by the UK government having the most significant influence. We have understandably seen the cancellation or suspension of some projects, most notably our in-person workshops, conference presentations, and some nationwide surveys. We have, however, taken steps to continue our work under different circumstances:

- We have moved in-person workshops to online webinars wherever possible, to ensure our survey

findings continue to be actioned and our partner trusts supported.

- Picker staff have embraced home and remote working, with excellent results.
- Picker will be offering complimentary Covid-specific questions for organisations participating in our staff experience programmes.
- Following the cancellation of the National Maternity Survey, we will instead run our own survey with interested trusts later in 2020.

Looking forward

2020 sees our 20th anniversary, and our continued commitment to delivering the highest quality person centred care for all, always. We will continue our successful collaboration with industry-leading partners, as well as working with regulators and other organisations to ensure that the most important experiences are captured effectively. In light of the

Covid-19 pandemic, we will continue to support organisations to understand its impact (see above).

Incorporating the latest technology is also vital to the continued success of our work: we are working on innovative machine learning and text mining technologies to ensure our findings are unbiased, reliable and consistent.



Funding sources and outcomes for beneficiaries

Picker is a registered charity, governed by a Board of Trustees to whom the Chief Executive and executive team report. All our funding is derived from our provision of independent surveys and research services.

Funding sources

- Universities and academic institutions
- Social enterprises and community partnerships
- International partnerships and collaborations
- Private healthcare providers
- Royal Colleges
- NHS organisations
- Professional bodies
- Charities
- Pharmaceuticals



Outcomes for beneficiaries

- Patients, service users, healthcare staff, and public voices are heard and used in co-design of services.
- High quality patient experience data is made available in the public domain for researchers and policy makers to use.
- Sound evidence available to measure the impact of changes and improvements.
- Regulators and national bodies have access to reliable information for performance and risk management.
- Improved patient, service user and staff experiences due to an understanding of the value of person centred care.
- Reliable data, products and tools facilitate improvements in patient, service user and staff experience.
- Best practice is shared in order to inspire the use of care experience data to improve person centred care.



Board of Trustees

During all or part of the period April 2019 up to March 2020.

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Stuart Bell CBE
(from September 2019)

Chairman

Professor Aileen Clarke
(from September 2019)

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