Simplyhealth and Picker Institute Europe proposal for improving patient information in private healthcare

As referred in the email correspondence to the CC, Simplyhealth has invited the Picker Institute Europe to make a joint submission as regards the principles for improving data capture and sharing outcomes that will enable informed choice by patients and funders alike, across the healthcare sector both private and NHS.

It is Simplyhealth’s opinion that the lack of quality data and information in the private sector relates to a number of data/information sources and applications, but that the two main areas are (1) clinical and patient reported data and (2) an opaque and poor appreciation of costs in the market.

This paper is intended to propose an approach and principles for the improvement of data, in respect of clinical and patient reported data in the private healthcare market.

1. Credentials of Picker Institute Europe

Picker Institute Europe is an independent not-for-profit organisation that works to make patients' views count in healthcare. It builds and uses evidence to champion the best possible patient-centred care and work with patients, professionals and policy makers to strive continuously for the highest standards of patient experience and pioneering patient experience measurement. Simplyhealth have invited them to support this submission to offer an authoritative and helpful response for the CC.

Picker Institute Europe pioneered methodologies of measuring patients' experience of healthcare in the UK. By 1998, the organisation that would become Picker Institute Europe had been formed, and helped carry out the first national survey of primary care patients to use this methodology for the Department of Health in England.

In 2002, Picker Institute Europe pushed for the establishment of an NHS national patient survey programme in England, under the then regulator, the Commission for Healthcare Improvement (CHI). Picker Institute Europe was a key source of survey development and co-ordination for CHI, and later for its successor, the Healthcare Commission, now the Care Quality Commission. Picker Institute Europe became an approved survey provider for the purposes of this programme and each year has produced surveys for hundreds of NHS trusts. It is therefore very well placed to support this submission.
2. Joint view of Principles for Achieving Quality Data across the Private Sector

Simplyhealth and Picker Institute Europe believe that there is insufficient information in the private healthcare market, not only in respect of clinical outcomes but also as regards patient-reported outcomes of treatments provided. Obtaining feedback from patients and taking account of their views and priorities is vital for bringing about improvements in the quality of care and ensuring informed decision making by patients and funders.

Simplyhealth and Picker Institute Europe believe that, to ensure any data captured and shared is both useful and enables informed decision making, it needs to be:

1. **of high quality** – Provided using robust and standardised methodologies across the entire healthcare market to ensure consistency and comparability;

2. **timely** - Published on a regular and timely basis;

3. **transparent** - Available to patients, providers and those commissioning healthcare as part of the open assessment of Quality care; and

4. **comparable** – Allows all providers (within the private healthcare market including primary care, secondary and home care) to be compared against each other in a way that not only highlights high and low performers but is fair taking into account any necessary data standardisation.

3. Approach for achieving quality data across the private sector

The task of establishing and improving data in the market should not be underestimated, but has to be recognised and addressed by all stakeholders, as the real risk of it proving too large a task to address will be that it has a continued detrimental effect on patients and funders alike.

It is the view of both Simplyhealth and Picker Institute Europe that, in order to establish credible data set(s) within the market, the private sector could benefit greatly from the experiences of the wider NHS and health care providers, where significant resource has already been spent and a wider pool of data for comparison and validation has already been established.

It is key to note that this is not new to the private healthcare market. The Patient Reported Outcomes Measures (PROMs) programme (hip, knee, varicose veins, hernia) does already include private sector providers and offers a solid set of benchmarks for the private healthcare market.

The NHS Patient Survey Programme (NHSPSP), started in 2002, including acute, primary care, mental health and ambulance organisations, illustrates how a number of core principles can underpin an approach to the survey programmes that are key to delivering robust patient experience data, meeting both national and local requirements.

Simplyhealth and Picker Institute Europe believe the following approach could be recommended for consideration, when assessing the need for and designing a program to collect quality patient experience data:
A consistent approach – allows organisations to monitor progress over time and to benchmark their performance, allowing the relevant regulator(s) and patients to be confident in the information provided and making decisions about quality when using it.

The NHSPSP carries out an annual post-discharge postal survey. An appropriate frequency for the private healthcare market may differ, as a result of a differing mix of clinical case loads and the potential use of online or email technology versus the NHS. However, this would need to be consistent across all private healthcare providers, not detract from the validity of the methodology.

A standardised survey methodology – all private healthcare providers are to use exactly the same sampling methodology, timetable, method of data collection and reminder system and that this service could be provided by an independent body.

A well designed questionnaire – that has already been developed with patients, clinicians and healthcare organisations for the NHS, that is thoroughly tested (to provide reliable results) and that has a core set of questions that remain consistent over time, to allow quality benchmarking.

The design of effective and thoroughly tested questions is essential to achieve quality data, which produces meaningful and actionable results. It is generally agreed that this is currently one of the key gaps in the private healthcare sector.

Analysis and reporting – a consistent and transparent treatment of the survey data (scoring, standardisation, etc). Not only is this key in ensuring credibility of the data reported and patient confidence, but the Francis report has highlighted the dangers of poorly designed and reported data and the potential effects of poor performance.

A coordinated approach – ensures that all organisations are undertaking the research in accordance with a standard Survey Guidance, using the same sampling, timetable, methodology, treatment of the data and reporting methods.

Clinical consultants and the various Royal Colleges are already in the process of establishing or extending clinical outcomes measures.

Simplyhealth would suggest that the Royal Colleges and consultants are in the best placed position to assess the need for and designing a program to collect appropriate clinical outcomes data for the private healthcare market as well as the NHS, the standards should be the same wherever the delivery of the treatment. Simplyhealth and Picker Institute Europe would like to comment on their work to add that:

Approach – that a similar deliberate, consistent, standardised and coordinated approach to collecting and analysing the data is adopted to ensure comparability in clinical outcomes, allowing for standardisation.

Clinical outcomes – that clinical outcomes would need to annotate the specific clinical stage of the patient’s conditions (e.g. cancer stage) and include estimates of safety (eg. toxic death rate for chemotherapy patients).

Not sole indicators – that clinical outcomes should not be analysed in isolation but within the context of informed patient decision making and careful management of patient expectations, for example: a knee replacement may have a good clinical outcome, having been successfully replaced, with no rework or infection, but if the patient was not properly informed that some activities (e.g. bending down on the
knee) may not be possible following the procedure, the outcome would be perceived by the patient as "poor", as full mobility has not been restored to that of a healthy patient without knee problems. Patients have reported that, following such a procedure, they have delayed further surgery or regretted having chosen to have a procedure performed, despite receiving a good clinical outcome.

Simplyhealth and Picker Institute Europe recognise that good work has already been underway in the NHS to establish sources of information regards hospitals such as Dr Foster’s Hospital Guide and other initiatives within the NHS and data available at www.ic.nhs.uk/ and would urge the initiative to be continued and extended further to include private hospitals. We would like to comment on the work to add:

- **Approach** – that a similar deliberate, consistent, standardised and coordinated approach to collecting and analysing the data is adopted to ensure a comparability in clinical outcomes, allowing for standardisation

- **Granularity** – that data would need to be available for individual private hospitals and areas of key specialism within the hospitals (e.g. cancer services), to ensure patients can make genuinely informed decisions about quality at a local level and not just based on the performance of an aggregated group of hospitals, which might distort the data. Accordingly the granularity would be best applied to providers within the private healthcare market including primary care, secondary and home care e.g. the delivery of chemotherapy at home and mobile screening units

- **Readmission rates, return to theatre rates, procedures with limited clinical effectiveness, day case surgery rates and mortality rates** – that these are all key indicators that should be included in the measures to be developed and extended to the private healthcare market

Simplyhealth and Picker Institute Europe would welcome bringing the private healthcare providers into line with the NHS trusts and allowing their quality reporting to be directly comparable across the entire healthcare market, so that all patients can make genuinely informed decisions.

Simplyhealth does not underestimate the scale of the task and would urge the CC to recommend a staged approach to the improvement of data and information in the healthcare market. The establishment of quality, timely, transparent and comparable information within the market and with NHS performance data set in a specific clinical area could be regarded as a successful starting point, from which learnings can be taken and progress can be made, to ensure informed choice by patients and funders alike.
Appendices 1: Additional information from Picker Institute Europe

The current NHS survey results are used at the national and local level. Picker Institute Europe carries out these surveys on behalf of over 60% of trusts and runs the co-ordination centre on behalf of the Care Quality Commission (CQC) – to design, analyse and report on these programs. The surveys allow trusts to compare their results and identify organisations where patients report a positive experience as well as those that do not perform so well. The surveys are centrally coordinated, but conducted by each organisation – giving local ownership, rather than a top down approach.

At the national level, the results from each trust are collated by the Coordination Centre (Picker Institute Europe) and contribute to national performance indicators published by the CQC. At the local level, trusts use the patient feedback to highlight areas where they perform well and to identify the issues where there is room for improvement. All trusts use the same core set of questions and have the option of adding additional questions from a validated bank of questions to ensure they can meet local needs and challenges.

The value of using a consistent survey methodology and questions is the ability to track trends over times and to benchmark performance, e.g. by type of trust, against the regional or national average. The national survey is often used by trusts as the annual benchmark (internal and external) against which they will monitor progress through the year, using snapshot surveys.

In addition to the national NHS patient experience surveys, similar programmes are running for NHS Staff Surveys and for PROMs.

The Staff Survey program is used to ensure that is possible to understand key measures of staff engagement and experience of working for their provider organisation alongside the collection of patient experience of care in that organisation. This program is starting to afford the NHS the ability to compare staff experience/engagement with patient experience and understand this important relationship in driving service improvement. Picker Institute Europe carries out over 50% of these surveys on behalf of trusts and runs the co-ordination centre on behalf of the Department of Health – to design, analyse and report on these programs.

Picker Institute Europe is an approved provider carrying out a number of the national PROMS programs, including the entire Cancer PROMs program for 2013.