INTRODUCTION
In order for patients to lobby for improvements to healthcare services, information on the quality of those services must be readily available and easy to understand. In 2007, the RCP Stroke Programme identified a need for a patient friendly report to make complex, clinically-focused audit results more accessible. The first patient centred reports were developed the following year. Since 2012, the Royal College of Physicians’ (RCP) Stroke Programme has run the Sentinel Stroke National Audit Programme (SSNAP). Leveraging the successes of previous RCP-run national stroke audits, the Sentinel Stroke National Audit Programme (SSNAP) continues to work with stroke survivors and patient and carer groups to improve patient reports, and to design new reports to help raise awareness of the quality of stroke care and services in England, Wales and Northern Ireland.

METHOD
The RCP Stroke Programme formed an implementation group with a majority of patients and carers to determine requirements for producing patient friendly versions of reports. Stroke survivors with aphasia (where speaking, comprehension, and the ability to read and/or write is affected) helped decide: what data to include; optimal ways of presenting data; and report layout. The Programme’s multi-disciplinary steering group (the ICSWP), other patient groups, and stroke charities revise and provide insight into each new patient report produced.

RESULTS
Key results are made accessible electronically and in hard copy to stroke survivors with communication and cognitive impairments through charts and graphs, symbols, and colour-coded maps and results are updated every 3 months. When first published these reports were downloaded around 200 times per quarter, but are now downloaded over 2,000 times per quarter. They are disseminated to hospitals, at national stroke conferences, and via patient groups.

In 2014 SSNAP also developed, in association with stroke survivors, an Annual Report on stroke care. Now in its second year, the report attempts to answer pertinent questions in stroke from the point of view of patients, using SSNAP data, clinical commentary, graphs, maps, and patient and carer quotes. SSNAP’s second Annual Report, ‘Is stroke care improving?’ was downloaded more than 20,000 times within 2 weeks of its publication, indicating its immense popularity.

Feedback indicates the usefulness of these reports for stroke survivors and carers, clinical teams, chief executives and members of parliament in instigating improvements in stroke care.

Case study quote
“I enjoyed it all (truly!) but just wanted in particular to commend the clarity of presentation. The amount of thought that has gone in to the layout, size, spacing, use of colour and explanations to ensure that it is as useful and informative as possible to everyone is obvious, and I haven’t read any other document for the public recently that comes anywhere close. It is good for me to know that such an exemplar exists.”

Stroke Survivor
“I just picked up and glanced through this report. Many congratulations to you, Pippa and other colleagues for making it so accessible to lay folk. As you would expect, I particularly liked the section at the end where the data was presented by patient journey outcome, rather than by provider care team.”

Vice President of national UK stroke charity

Conclusion
Stroke survivors have a powerful voice. Audit reports tailored to their needs are effective to increase knowledge and drive change. Involvement of patient groups is key to transforming complex data into information understood and used by stroke survivors and carers.