Editorial: Integrated care – power to the patients?

The participants of the most recent International Conference on Integrated Care will have
now made their way home, undoubtedly still buoyed and exhilarated by many fascinating
conversations. They will have had countless impressions of innovative and, sometimes,
ground breaking approaches in integrated care research and practice.

Looking back over these days in the Belgium city of Antwerp, I am struck in particular by
the way in which patients themselves have moved centre stage in many integrated care
programmes and discussions. Increasingly, the role of patients in designing and producing
care is emphasised and receives attention, be it through a renewed focus on their health
literacy, their competencies to navigate still fragmented health systems or their ability to deal
with organisational or professional boundaries.

I have long argued for a more prominent place of patients in our conversations about
integrated care solutions. The predominance of professional and organisational perspectives in
integrated care research and practice was always unhealthy, even though perhaps initially
necessary in order to understand the barriers to improving health care services. Yet mapping
patient experiences, whilst common practice in business studies, happened far too rarely in our
research community, where sophisticated and overwrought modelling often buried common
sense approaches to difficult, yet simple problems of fragmentation and lack of collaboration.

Learning from those who use services comes natural to those working in business, since
business leaders, by definition, need to understand the needs of those they serve. It throws a
revealing light on health service research and integrated care that patients rarely receive the
same red carpet treatment in our field. We profess to do integrated care for patients but when
it comes to asking them the simple question of what would improve their journey through our
health systems we treat their answers as launching pads for convoluted research studies into
organisational complexity and multiprofessional compartmentalisation.

I am not advocating theoretical Luddism or ignorance of the, at times, beautiful modelling
that produces novel insights and knowledge into why something works (or does not). But I do
think that often the answers to issues of fragmented care are simpler than we think. It may be
the consultant picking up the phone to their colleague to discuss a case rather than filing a
message on the system that may or may not be seen. Or it may be the nurse double checking
that the next shift has actually been updated on the patient that is to be transferred to the
other unit.

So what about the patient in all this? Some of us are hoping that a growth in patient power,
in combination with increasing competencies and health literacy will bring about improved
patient experiences. As with everything else, however, there are likely to be winners and
losers with this scenario. Activist patients are most likely to be found amongst the more
educated and health system savvy citizens. It may be normal for some to look up the
performance data of a consultant. Like many others, I still find it difficult and, more
importantly, struggle to understand that it should be a task of mine to sift through
performance data to identify the best doctor for a given specialist care task. In other
industries we have a floor threshold, where providers have to offer you, as a client, a minimum
quality of service. In health, you have hope, a prayer and usually a disclaimer form to sign.

In other words, the weakest link in medicine and health services has always been (and still
is) the patient, especially in universal payer health systems such as the NHS where choice is
practically non-existant. A case in hand is the tussle over health care data. Whilst some call it
(euphemistically?) “patient data”, everyone who has tried to get access to their data knows that it is anything but. Services usually understand it to be their data, not the patient’s. And it is up to the services of course to do with it what they think is right, including providing it for research purposes. The warm words of NHS digital notwithstanding, for example, the wholesale sale of NHS data has long begun, with or without patients’ consent [1].

This brings us back to integrated care which is, by definition, supposed to be the triumph over organisational and other boundaries. Given that health and social care boundaries are the most prominent culprits in this area, patients would need to have competencies in two, if not several, disciplines, potentially making them more knowledgeable and skilful than their professional counterparts. Is there any chance of that any time soon? More realistically, perhaps, we should try to listen more to patients (and service users) and look for simple and pragmatic solutions which bring real relief to those who need help and support here and now.

In short, we have not quite figured out how to give patients an effective voice in health and social care service commissioning, design as well as delivery. Advocacy and choice may be part of the solution, but all these come to a shuddering halt when patients are moving into the realms of social care. Whatever the solutions are that may be presented at future integrated care conferences, listening to patients more may be a good start.

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Note

1. NHS in England have established an “opt out” clause for patients. Take up of opting out hovers around 5% in England.