

## Ten lessons for integrated care research and policy – a personal reflection

In January 2019, the University of Birmingham hosted a one-day workshop organised by the *Journal of Integrated Care* and the *Integrated Care Researcher Network*. As previous editors of the journal, it was a very proud moment to host such an event, with an audience that felt very much like a “Who’s Who” of the UK integrated care research and policy over at least the last 10 years. With the current editor organising and chairing the event itself, we were privileged to be there solely as participants – and this gave us the opportunity to reflect on the key lessons that we would take away from the workshop (and from all our years writing for and editing the journal, providing advice to government and supporting local integrated care initiatives). These are just personal reflections, but we were struck by how clear and consistent many of the key themes were across different policies, studies and projects developed over time in different policy, financial and geographical contexts.

Our ten take-away messages were:

- (1) Integrated care as a triumph of hope over experience? Policy aspirations are remarkably similar over time (despite previous initiatives not being perceived as delivering what was intended).

Our experience at the workshop and in our research and policy work more generally is that policy makers and local leaders periodically develop initiatives to promote more joined-up care, that these can feel similar in nature over time and that – in a fast-paced policy context – we can sometimes seem to lack organisational memory when developing new approaches. For us, there are at least three potential aspects of this. First, it is easy to forget what has gone before, and for the same underlying ideas and approaches to recur over time. At the initial workshop, it was fantastic to hear lessons from New Labour’s “Integrated Care Pilots”, which have so many similarities to previous “Care Trusts” or to more recent “Pioneers”, “Vanguards” and “Integrated Care Systems” – but which many people not directly involved in the original Pilots may long since have forgotten. Second, there seems to be an over-optimistic assumption about what is possible to achieve and how quickly this might happen. It could probably have been said about any integrated care initiative over the last 30 years, but Erens *et al.* are clear that:

The current study shows clearly that the benefits of integrating health and social care are unlikely to be apparent for several years, and expectations of policy makers to see rapid improvements in care and outcomes are likely to be unrealistic.

Similarly, the evaluation of the “Vanguards” by Jenny Billings and colleagues acknowledges that:

As a flagship national programme provided with significant additional funding, the Vanguard programme was, by necessity, ambitious. As a result, many of the assumptions underpinning both local and national plans were probably over optimistic, given that the programme as a whole only lasted three years [...] Generating sustainable local change in complex organisations takes time, and it may have been unrealistic to expect Vanguards to have had a significant impact in such a short time.

Third, as policy shifts over time, what success might look like also seems to change – so that what we are trying to deliver and to evaluate is usually different from what we set out to achieve or to understand at the beginning. In subtle ways, many of the papers in this special



edition imply a degree of “creep” over time, as “integrated care” becomes the solution to a current issue that was not necessarily the main focus when the initiative started. This certainly seems to have been the case with the Integrated Care Pioneers (as one example), with Erens *et al.* observing that:

While some progress in achieving local integration objectives was evident, it was also clear that progress can take considerable time. In parallel, there appears to have been a move away from aspects of personalised care associated with user control, perhaps in part because the emphasis of national objectives has shifted towards establishing large-scale ICSs [Integrated Care Systems] with a particular focus on organisational fragmentation within the NHS.

With the “Vanguards”, there could also be tensions for local sites and account managers as the focus of local innovation began to be judged against a smaller set of national indicators:

Over time the monitoring of Vanguards was stepped up, with funding for the final year of the programme linked to performance against a small number of nationally determined metrics. Whilst the Account Manager role was intended to be supportive and developmental, in some cases they were perceived as taking on a more performance management role over time with the Vanguards. This potentially led to tensions around their role within the overall programme and to distrust between types of actors in the system.

- (2) Integrated care as a victim of hyper-active policy-making? Whilst some topics arguably receive insufficient policy focus, integrated care has been the subject of too many different policy initiatives – and this can cause chaos at local level.

In recent years, the English health and social care system has been developing and learning from Integrated Care Pilots, Integrated Care Pioneers, Vanguard New Care Models (including Multispecialty Community Providers, Primary and Acute Care Systems, Acute Care Collaboratives and Urgent and Emergency Care Networks), Accountable Care, Integrated Care Systems, Primary Care Networks and probably more – and other parts of the UK have been developed other initiatives and approaches. Some areas of the country will have taken part in several of these initiatives over time (sometimes at the same time), and everywhere will have experienced multiple, often over-lapping policy priorities which can be hard to keep track of – let alone to implement in a coherent way at local level. In the paper on the Integrated Care Pioneers, for example, Erens *et al.* present a bewildering array of (often inter-connected) activity taking place at local level under this banner – and many things that were probably taking place already to some extent and/or taking place in non-pioneer sites (such as community-based multi-disciplinary teams, social prescribing, care navigators, use of the voluntary sector, shared patient records, shared health and social care budgets, community hubs, etc.). At best this can be extremely confusing, and at worst it can cause chaos – and certainly makes any meaningful evaluation really difficult. When testing a new medicine, researchers try to minimise the impact of any other factors that might influence the outcome so that they can be as sure as possible that the main cause of any health benefit is the medicine that the person is taking. With integrated care policy and practice, such simplicity and precision is impossible. Unpicking what is actually happened, what caused what, what might have happened anyway, what might be due to extra support/funding rather than new models and what things work in combination with others but might not work on their own is, therefore, a major judgement call (and at worst might simply be educated guesswork):

- (3) Integrated care as a policy which can over-promise and under-deliver? Over time, different initiatives have set out very ambitious goals, failed to focus sufficiently on the practicalities of delivery and the end result has been under-whelming.

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This has long been an issue with policy pronouncements and national initiatives to integrate care, and certainly seems to have been the case with the approaches showcased in this special issue. In the case of the Vanguard, for example:

The Vanguard programme was established at a very rapid pace, with the programme starting within a few months of the initial submission of expressions of interest. This meant that those providing support and those in local Vanguard were required to work very quickly to get things up and running. In addition, whilst the programme was initially established as a three year programme, funding was allocated in an annual cycle, leading to uncertainty [...] By the third year of the programme, there was perceived pressure to demonstrate improvements, with the final year's funding conditional upon improvements in a narrow range of national metrics. Respondents argued that the programme needed to "hold its nerve", with benefits more likely to accrue over a longer time period.

Later on, the same paper stresses:

The time consuming hard work required to integrate care across organisational boundaries, and the need for protected time as well as a strong support function if local organisations are going to be able to build the relationships they need to work more closely together.

As Edwards argues:

Complex change in large systems made up of clinical professionals who already have well established ways of working is difficult. Given that this is well known, the level of optimism about the time required or the likely size of the effect that can be expected is hard to explain. It is possible to create significant positive changes [...], but it is a long-term project.

Of course, the risk of over-promising and under-delivering is potentially even greater in the current policy context, where the "integration paradox" identified by Erens and colleagues means that integration is even more important than ever before, but also even harder to achieve in a challenging policy and financial context:

- (4) Integrated care as a buzzword which means all things to all people? Although everyone agrees that integrated care is important, it is rarely clearly defined – and lots of national initiatives are often a mix of very different service models, ways of working, relationships and desired outcomes, some of which may not have much in common with each other.

While the language of partnership and integration is widespread, all contributors to the workshop stressed the diversity of the approaches that they had evaluated, and the difficulty of drawing general lessons from such heterogeneous service models. Reflecting on key lessons from New Labour's Integrated Care Pilots, for example, Richard Lewis describes projects seeking "vertical integration" (between community and hospital services) as well as "horizontal integration" (joining up organisations providing similar services), highlighting a wide range of differences between projects in terms of "scale, clinical focus and local contexts". While this can mean that a number of different initiatives can be taken forward under the banner of the same overarching concept or project, it also runs the risk of different stakeholders using the same language to refer to very different ways of working – effectively finding themselves divided by a common language.

This can be exacerbated by a lack of agreement over what success would look like. As an example, Erens *et al.* chart changes to priorities over time, listing these under headings such as "reducing unplanned hospital admissions", "patients/service users better able to manage their own care", "patients/service users experiencing more joined-up services", "improving quality of care" and "improving quality of life" – arguably these are very different things and might be achieved in different ways. Any initiative which seeks to do all of these at once

(or can be interpreted by different stakeholders as being capable of doing so) is either a genuine miracle cure – or is likely to disappoint at least some:

- (5) Integrated care as a way of identifying unmet need? Saving money (or using existing resources more effectively) often seems to be a policy goal, yet many initiatives seem not to do this. Indeed, by identifying unmet need and improving access to services, integrated care may actually increase costs in the short-term.

As Nigel Edwards argues, schemes which provide more intensive management of patients may have clinical benefits, but they can also result in the identification of additional needs (both previously undiagnosed conditions and the potential medicalisation of social needs). This may have been the case with New Labour's Integrated Care Pilots, as but one example, with the potential for more efficient case finding to lead to increased rather than reduced emergency hospital admissions. Even where integrated care may reduce use of hospital services, Edwards makes it clear that any potential savings are typically hypothetical and "difficult to convert into cash savings". Put even more starkly, if we free up a hospital bed (in theory), we often cannot close it, and typically just fill it with someone else – so that we end up paying twice (once for the initial bed, and once for the integrated care project that was trying to free up beds):

- (6) Integrated care as a source of ambiguity for people using services? While integrated care is often presented as a way of improving outcomes for patients, patients themselves do not always see it like this.

Integrating care is usually presented as a way of improving the quality of care and patient experience, and lots of practical experience suggests that this can be the case. However, the way in which integrated care initiatives are experienced by people using services can be more ambiguous than this. Anecdotally, some people with whom we have worked who use mental health services have said that they sometimes find it helpful to have separate health and social services, so that they have a potential ally from a more socially orientated social care system against what they perceive as the power of a more medically orientated psychiatrist. Having a single system of health and social care in these circumstances might bring lots of advantages, but also means that there are fewer places to turn if you do not agree with what the psychiatrist is saying is best for you. Similarly, people using services often say that they value relationships with individual workers who they feel have the right value bases and who know them and care about them.

In some integrated care initiatives, one of the aims can be to systematise previous ways of working and to make our structures and approaches more efficient and better able to respond to high volume/significant service pressures. In these situations, an unintended consequence may be that the individual now receives care from a better organised, more integrated system – but loses access to valued individual relationships in the process. More often, the patients we meet do not really know or care how services are organised – quite rightly, they see this as an issue for services themselves to resolve. Instead they value accessibility, empathy, being treated like a human being, finding someone who can help in practical terms and people who build confidence and make people feel at ease. Here, whether or not a service is integrated might make a difference, but it is not really the main issue. A final observation here is that some initiatives can begin by focusing on user experience and outcomes, and then drift back into issues that really matter to the system, but feel less pressing for individuals using services. Thus, in the national evaluation of the Integrated Care Pioneers, for example, there seems to have been a potential shift away from greater personalisation of care, users having a greater say over their support and being better able to manage their own care towards a more organisational focus on overcoming the fragmentation of NHS services. In the earlier Integrated Care Pilots, more patients received a copy of their care plan, but

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fewer people could see a nurse of their choice, felt their preferences were taken into account or felt involved in their care:

- (7) Integrated care as a source of ambiguity for staff? Working together in new ways seems to present significant challenges to health and social care professions, but can also be experienced positively (and this is possibly a neglected issue that needs further exploration).

In some of the literature, a key barrier to more effective joint working is believed to be the attitude of front-line practitioners, who are often trained in uni-professional settings and cultures, who can feel suspicious of losing out in terms of power and status to other groups, and who can see integration as threatening their professional identity and contribution. Much of this literature focuses on the training and organisational development interventions that might overcome such challenges and help people feel more comfortable working in new ways. At the same time, integrated care might also be a source of staff satisfaction. In the Integrated Care Pilot evaluation of 2010–2012, for example, many staff were positive about new ways of working and felt that they were delivering better care. Working with others can also broaden our world view and offer access to greater training and career development opportunities, as well as contributing to a sense that we are at the “cutting edge” of health and social care and achieving benefits for the people we are there to serve. As Jenny Billings and colleagues quote:

I think it's been fantastic, and anyone who's worked on it, it's been a joy to do, a joy to see, 'cause you don't often get the opportunity to do this, and see that.

I love the way it just feels different from what we've done before and actually potentially quite transformational.

In our view, these are under-researched topics, and the importance of staff perceptions, attitudes and experiences may have been neglected relative to other aspects of integrated care:

- (8) Integrated care as a means of reducing hospital admissions is the wrong lens? Typically, hospital admissions do not reduce as a result of integrated care projects – but this probably is not the right measure of success.

Nigel Edwards makes the point that the costs of care between hospital and community settings are often not very different, so that reducing admissions does not necessarily lead to savings. He also demonstrates how hospital admissions may not be the best metric to use to judge success, with either small effects or even an increase in admissions. However, even more fundamentally than this, a tendency to over-focus on admissions can mean that adult social care is seen as an adjunct to the NHS, and a way of producing savings for the health service. While there may be many benefits from joint working, this means that we might fail to appreciate the importance of adult social care in its own right, and focus overly on services for frail older people (without thinking about other services, such as those for disabled people of working age, people with learning difficulties and people with mental health problems):

- (9) Integrated care as an example of the limitations of national evaluations? The studies presented were detailed, rigorous, carefully conducted and impressive in their scale and scope. However, most of the key findings are ones which many people would have predicted in advance. This is still important, but raises the question as to whether there are better ways of commissioning research in future.

Many of the integrated care initiatives explored here and in recent years have been extensively evaluated, by large, experienced teams, often in world-leading units and with impressive rigour, attention to detail and nuance. The research has been carefully and sensitively conducted, and teams have reflected hard on how to undertake their work in a complex and constantly evolving environment. Subsequent reports are very carefully written,

very detailed and subject to multiple internal and independent review before publication. Such research is now large in volume, impressive and has benefitted from significant public funds (even if the funding available never feels enough for the size and complexity of the evaluation challenge at hand). Despite all this, many of the papers included here and the broad studies from which they derive report similar themes over time – almost to the extent that we could probably guess what the next national evaluation of integrated care initiatives is likely to say before it is commissioned, let alone before it reports.

None of this is the fault of the research teams involved, but this does start to raise the question as to whether commissioning large, long-term national evaluations is the best way of spending money and of finding out what we need to know. We would love to conduct an experiment where the audience at the initial workshop on which this special edition is based drafted an executive summary of an evaluation of the next major national integrated care initiative, and then stored this away to compare against the actual executive summary of the subsequent study. Our hypothesis is that such an exercise might capture the overall tenor of subsequent findings fairly well and perhaps get it 80–85 per cent right in terms of key themes and lessons.

While confirming that we genuinely know what we think we know will always be crucial (and provide an important safeguard against assumptions, misunderstandings and complacency), integrated care in particular seems a field that might benefit from more rapid, real-time and action-orientated approaches – perhaps asking questions such as “how can we best make this work in practice” rather than “does it work”?

- (10) Integrated care still matters! In spite of all these caveats, joining up the care of people with cross-cutting needs is still essential, and none of the above should be an excuse for not doing this.

What struck us most from the workshop is that many of the speakers and the audience have been working in this field for decades, constantly striving to improve our knowledge and to help this new knowledge have an impact on policy and practice. While some of the “lessons” above might seem a bit negative, the event itself was really positive – with participants wanting to pool their experiences in order to work even harder to improve policy, practice and research in future. While there are ongoing challenges and complexities, no one was saying that we should not be trying to join up care for people with complex of multiple needs, and no one seemed to be arguing that research is not needed or cannot make a positive difference. Of all the ten lessons in this short personal reflection, this seem to us the most important – care can be poor when it needs to be but is not joined up, doing nothing is not an option and this agenda really matters.

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