Building a 'clinical satnav' for practitioners and patients

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BCS

The Chartered Institute for IT

3 Newbridge House,

Newbridge Square,

Swindon SN1 1BY

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Healthcare must catch up with other sectors: to save more lives we need fully computable knowledge

Decision support requires computable knowledge to improve the excellence and efficiency of healthcare and empower patients.

Knowledge should be formatted to enable high quality, computer-driven decision support, so it sits at clinicians' fingertips... not in a pile beside their desks or in their inbox.

"Patients think we know everything about them, their problems and where to go next," explains a doctor. "Until something goes wrong, and they recognise that's a mirage. They realise that we're often flying fairly blind, scrabbling around for information on them, trying to work out what their symptoms mean.

This involves both *data* about the patient's history and current state, and *knowledge* about how to interpret and use that data. Yet, we could have the equivalent of a "clinical satnav" for practitioners and patients that suggests next steps (like the *knowledge* of how to calculate optimum routes), given the available patient health *data* (the equivalent of location, destination, traffic conditions and road works)."

Will artificial intelligence (AI) fix this? AI can help, but it depends on reliable data. Where we have good data, AI can produce some kinds of knowledge from routine data (such as age-specific rates of drug side effects) that is more persuasive than small research studies. However, there are other kinds of knowledge (such as the effectiveness of a drug) that challenge AI methods used with routine data. This is partly because of the volume of data, but also because retrospective studies are subject to inherent limitations.

This White Paper sets out what computable knowledge in healthcare could achieve. It outlines the challenges we need to overcome - technical, cultural, institutional, financial and strategic - for shifting healthcare systems into both creating and using computable knowledge. It also explains about the consequences of not resolving those issues: unnecessary and increasing health spending, inefficiency, patient and professional dissatisfaction and burnout.

Healthcare decision support lags behind other sectors

Widely available healthcare decision support is needed and is possible. It already exists to a limited extent as a cottage industry. This cottage industry assembles lots of small elements of computable

knowledge using different tools and standards, limiting the potential for scaling up the industry. However, in other fields beyond healthcare, digital knowledge gathering, analysis and support for personal and expert decision-making is commonplace. Busy healthcare professionals, increasingly seeking digital-first sources of information, will demand no less. So, healthcare science, regulators and guideline providers need to satisfy that demand if they are to remain relevant to practice.

This yawning - and growing - gulf between the expectations and realities of healthcare contrasts starkly with other sectors. Banking, shopping and travel process information, data and knowledge almost seamlessly. People and their needs are understood so intimately that there's little difficulty recommending suitable lovers, films, food and holidays for them. Why, then, is healthcare knowledge management so immature? Why, when Britain is a leader in health research do we so rarely produce *computable* knowledge?

Health systems hold lots of knowledge, yet it is often inaccessible at the point of care. It's sitting in journals and guidelines, often in email inboxes or in piles next to desks. Airline pilots have split-second, sophisticated decision support systems to guide their actions. Automated systems will soon manage driverless motorways. We have already seen sophisticated decision support systems land the Perseverance rover on Mars. But it still seems to be rocket science in the NHS or - to be fair - most health systems.

We currently lack the infrastructure for computable knowledge in healthcare. Right now, our situation is like trying to engineer the Industrial Revolution without building the coal mines and railways. The economic and social benefits of computable knowledge to the UK could be as important as those innovations – see Appendix.

In the UK, important initiatives in this field are now underway by NHS England, Health Education England, NHS Scotland and NICE. This White Paper aims to support those programmes and suggest specific ways forward.

The high cost of poor clinical decisions

These costs can be measured. In the US, "Adults and children only receive recommended care about 50% of the time," the *Journal of the American Medical Informatics Association* reported in February 2021. "Individual clinician decision-making is commonly associated with mindless, or unwarranted variation (deviations from best practice, not based on evidence or patient preference) and associated with waste, morbidity, and mortality", reported the journal. This problem, reports the journal, is not confined to generalists, underqualified clinicians or those approaching retirement. "Even specialists claiming to follow best evidence do not consistently do what they say."

This is not the fault of clinicians. They're typically overwhelmed by poorly processed data and knowledge. Scientific advances have outpaced the capacity of the human brain to curate and apply to patients all the amazing insights that are available. Clinicians need, beside them, not a pile of guidelines but the processing speed and interactive capacities of computers. This would keep doctors, nurses, pharmacists and other health professionals in the driving seat of excellent decision-making. And, of course, patients.

Clinical 'satnav' to guide practitioners

There is an opportunity to develop, at last, what the doctor-patient relationship is designed to deliver: a dynamic link between scientific learning and what's known about the person. Where helpful, high quality decision support would guide clinicians through a series of steps: which tests to order, evaluation of the results, possible diagnoses, options for care pathways and treatments.

Missing this opportunity carries a high price. Despite everyone's dedication, the price being paid in health system underperformance and inefficiency, where fatigued clinicians are overburdened both cognitively and bureaucratically. Much more could be achieved, potentially for less, with a better experience for patients and clinicians.

Why is this transformation so hard to achieve? Surely computers can read and perform the task? Yes, they can read. But, computers cannot use journals and guidelines to apply knowledge.

Computable knowledge is key

There is a solution which is simple to discern though challenging to implement. We need to format healthcare knowledge into a standard computable form. This translated knowledge needs to be stored in a quality-assured e-library that people and systems can access using open standards. There is a growing momentum behind the need for computable knowledge. But there is still a lot more to be done to make sure it's standardised and properly quality assured.

A cottage industry already exists that makes healthcare knowledge computable to underpin specific decision support systems. But the standards and quality assurance are proprietary, not open. This means they vary from company to company and cannot form a shared library. It also leads to duplication and potential contradictions. The design of decision support systems is often inadequate to have real value. Often clinicians are so annoyed they switch them off or cancel warning messages without reading them.

Coding and regulatory challenges

Making knowledge - including NICE guidelines and intricate care pathways - computable means breaking down what is known into small, tightly defined fragments, which are then coded (either 'tagged' by condition, or actually translated into an algorithm). These fragments require regular updating, which can be automated once a suitable curation system is in place. And, because healthcare is riskier than other fields, high quality encoding is essential to ensure people get the right computer-recommended diagnosis or treatments and not the wrong ones.

Strategy and leadership needed

Getting all of this right requires leadership, long-term strategy, funding, multi-disciplinary collaboration plus implementation across, and within, all parts of healthcare institutions. These elements are beginning to come together. The goal is attainable. And we can make gradual progress through a series of manageable, safe steps.

The only way is up

For all these many reasons, healthcare systems have little choice. They need to take advantage of new ways to organise and express their knowledge and connect it to patient data. We set out some next steps so that policy makers can create an agenda for change that reaps the benefits of making healthcare knowledge computable. So, let's understand the challenges and how to overcome them.

Ten challenges

How can we create fast, relevant, point-of-care healthcare decision support that's trusted?

Achieving this goal requires clear leadership and strategy, professional and public engagement, sound regulation and readiness for change, multidisciplinary working and e-librarians.

However, healthcare science faces extra challenges compared with most fields developing decision support services. Clinicians must, first and foremost, do no harm. Therefore, their decision support must be safe, accurate and high quality or it will immediately lose dependability and trust. Decision support must also be nuanced to fit the patient and multiple combinations of conditions. A stroke might be caused by a blood clot. Alternatively, it might be caused by a bleed. The first cause requires life-saving thrombolysis (thinning the blood). However, that treatment could kill those patients whose strokes are thanks to a bleed. Clearly, the nuance of healthcare decision support has life and death consequences.

A big question hovers over this field: how can we create safe but fast point-of-care decision support, given that digital publishing tends to drive out quality and nuance? Here are a few of the challenges.

'Every step must be broken down, with each term clearly defined to avoid confusion and mistakes.'

1. Healthcare knowledge is complex and requires precise expression

It's difficult to frame healthcare knowledge in computable format because the process of clinical decision making is so complicated and precise (and yet sometimes messy or tentative). Every step must be broken down, with each term clearly defined to avoid confusion and mistakes. A clinical informatician explains: "Take for example, guidelines for treating rheumatoid arthritis. There is no such thing as a patient who simply has rheumatoid arthritis. There are probably four or five sub-types of patients.

"What if the patient has had a bone marrow transplant? Do you mean patients with rheumatoid arthritis who've already been treated for 10 years with methotrexate? Teenagers with rheumatoid arthritis need to be treated differently to someone who is over 60 with impaired renal function. If you are going to provide decision support, based on guidelines, you must be able to map each pathway, covering each sub-type. Each pathway should define the right drug, the right dosage. Should it be injected into the joint? Is a tablet best?"

"We've got all the technical power in computing to develop highly sophisticated decision support. However, it will only work well if the meaning and implications of differences around conditions and disease are precise expressed and standardised."

2. Who decides what knowledge is computable?

Traditional healthcare guidance is typically couched in language with rather vague wording that clinicians are able to interpret. Computer-driven decision support needs knowledge to be presented in a much more precise and unambiguous form. A guidance expert asks: "Often the knowledge can justify that clear instruction. But whose job is it to go that extra step and develop a more directive pathway? Does that belong to organisations such as NICE or somewhere else?"

"A classic example of defining language more clearly is 'severity'. Guidelines will say 'depending on severity', try this drug or that drug. But severe is an idiosyncratic term that people define in slightly different ways. It can be made more precise on a sliding scale – for example, if x, y and z apply, then, in that case, severity equals 1." Where medical knowledge does allow more precision, then it could be made instructional, converted into algorithms and thence into computer-driven decision support. Of course, not everything can be made algorithmic, so sometimes advice can only state; 'Try this drug and, if doesn't work, then try this drug'."

"Think of decision support as continuing professional development. What we learned in medical school may now be frowned upon or apply only in certain cases."

3. Connecting electronic patient records to healthcare knowledge

Much content in electronic patient records (EPRs) is still written in free text. The challenge here is to structure and code this material so that decision support can interpret the patient record and set out pathways for an individual patient by selectively combining clinical knowledge with the EPR data.

4. Data must be complete, and decision-support prompts well-designed

Understandably, many clinicians feel burdened by typing in patient data. However, if it is incomplete or inaccurate, then the decision-support based on incomplete data will be unhelpful. Additionally, some clinicians may not respond carefully enough to decision-support prompts. For example, in dropdown menus, the top term – say eczema – is typically chosen more often than a lower one like, say, psoriasis. Other clinicians may reject decision-support as questioning their expertise. However, a doctor explains: “We should think of decision support as a form of continuing professional development. It is almost impossible to keep up with all the new research in any given clinical field. Yet it’s vital to have better access to it, because what we learned in medical school may now be frowned upon now or apply only in certain cases.”

5. Computable knowledge needs to be accessible, with updates built in

Computable knowledge is the raw material from which decision-support is created. It needs to be in a standardised format. Accessibility demands that the knowledge is held in common in an open e-library that is well-indexed.

Recommendations using open standards from research, regulators and guidance-creators are the raw material of decision support, but they need to be regularly updated as the science advances. So, for example, recommendations for treating COVID-19 have changed frequently. Computer-driven decision support is an excellent way to bring these changes into clinical practice rapidly. However, it requires a commitment and capacity to frequently update both diagnostic and care pathways as well as their digital equivalents. The computable healthcare library in the Cloud will be a busy, labour-intensive place.

‘This has to be a highly collaborative process between clinicians, knowledge engineers and computer scientists.’

6. Multi-disciplinary working is vital for quality assurance

Building these decision-support systems means melding clinical and informatics expertise into relevant, workable, accessible advice. An informatics academic explains: “How do you create multidisciplinary teams that involve clinicians who must assess the evidence base to develop recommendations and determine which parts of the recommendation are computable and which are not? They need to come up with a sufficiently precise definition of a recommendation so that it can be made computable. All of this need to be a highly collaborative process between clinicians and knowledge engineers. Otherwise, there is a wall between them: the clinicians throw something over the wall to the engineers who then make all sorts of assumptions about what it means and what it doesn't mean, which is where these things always go wrong.”

Another expert in this field states: “There is a real need for a multidisciplinary approach where participants trust the others’ experience and expertise. Digital practitioners and informaticians should work alongside clinicians and public health advisers. They must communicate to understand the opportunities, the language barriers between them, the political drivers, and what people see as

important. I've not yet seen a true multidisciplinary conversation where there's a full shared understanding of this space."

'The concept will work only if there is standardisation around how to define data and care pathways.'

7. Coding health knowledge and updates into formats that computer can interpret

Computable biomedical knowledge is still in its infancy. Should it be done in-house or outsourced? Should the task be left to the private sector? A digital healthcare expert explains: "Big players in the digital space such as Facebook and Microsoft, are all looking at healthcare. But, even if Google, Apple or Microsoft take this on, the concept will only work if there is standardisation around the data and care pathways. They could build a brilliant algorithm that works for a group of patients, but it won't work safely and to a high quality unless all of the terms in their pathway have been used correctly."

8. Healthcare decision-making must be a step-by-step process

Decision-support is like a dance between the clinician and the support tool. Each must stay in step with the other or the clinician is wrong-footed, rather than guided. The process is a series of stages, beginning with what's known about the patient, and moving on to what tests to do, evaluating results and later suggesting possible diagnoses and treatments. An informatics expert explains: "Decision support must try to capture clinical decision-making patterns. By following the logic of real decision-making, the support speeds up and facilitates each step along the way with relevant knowledge and advice."

9. Regulating and monitoring the development of decision support

Oversight by a trusted government agency will be required to guarantee safety and quality, regardless of who performs the tasks of formatting computable knowledge and developing new decision support systems. A healthcare informatician suggests: "We could consider something like the model used for the Medicines and Healthcare products Regulatory Agency." The MHRA has licenced "Notified Bodies" that do the testing and certification of medical devices. We could have something like that to quality assure decision support tools." Adherence with decision support advice also needs to be monitored anonymously at organisational or national level so that we can change guidance based on understanding of both expected and unexpected variations.

'Without a clear strategy, division of roles and responsibilities and coordination, this ambition could stall.'

10. Leadership and Strategy

Health systems, like all organisations, struggle to lead change because they are restricted by their commitment to business as usual. There is no single stakeholder within government with overall responsibility for leading and implementing this complex initiative. Government leadership is required to set out a strategy that defines the goals and the roles of the many different parts of healthcare required to create and implement the strategy.

Planning and delivery will not only be inter-departmental (bringing together, for example, those responsible for standards and guidance setting), but also those charged with healthcare digital strategy, regulation, capital infrastructure and clinical delivery in primary, community, social and secondary care. It will also be multi-disciplinary, requiring the collaboration of, for example, informaticians and clinicians.

Health is a devolved policy in the UK. So, for example, NICE provides national guidance and advice to improve health and social care in England and Wales. But the Scottish Intercollegiate Guidelines Network plays this role north of the border. Some conditions do not have published guidance from an authorised UK body so practitioners rely upon American or European guidelines. We will need to clarify the rules for how Britain's various guidance standards should be used for decision support. Ultimately, a global framework in also required, within which jurisdictional systems can operate.

Next steps

We need to collaborate, pilot and recognise the opportunities and the challenges – and the dangers of failing to act.

It makes sense to start by piloting creation of computable knowledge and decision support in areas where progress will reduce clinical burden and enhance safety.

The development of computer-driven decision support will place clinicians in the driving seat of ever-improving, high quality learning healthcare systems. Its wider availability will underpin patient empowerment and self-care. Implementation of computable knowledge and decision support will also be vital if policy makers are to succeed in devolving as much healthcare and resources as possible from secondary to primary care.

'A digitally-enabled system would make clinicians' lives easier, the system itself healthier, and result in a better care for all of us.'

The infrastructure required for developing such decision-support – translation of knowledge into computable formats – also opens the door to a further major development. Once computers can process healthcare knowledge and connect it to patient data, a truly learning healthcare system becomes much easier. Machine learning - searching for patterns in system-wide records of practice and patient experience – becomes possible. It will provide a new source of knowledge and insights that will sit alongside traditional scientific learning. It will further improve the excellence of healthcare delivery and enable more personalised patient care, drawn from analysis of so many different patient experiences. It will also help to improve the quality of decision support because it will be possible to examine which types of support are associated with the best outcomes.

We encourage healthcare policy makers, managers and practitioners to continue exploring and discussing how they can make the most of the opportunities outlined in this White Paper while also overcoming the challenges it describes. There are already promising signs that these challenges are increasingly recognised, for example NHS England has identified decision support as a priority for the new Transformation Directorate. NHS Scotland already has a national decision support strategy and service. NICE is actively exploring ways to make its guideline content computable. Health Education England provides guideline-based decision-support to the frontline, both as a point of care tool and a learning resource, and is investigating cultural, behavioural and motivational factors influencing uptake. For the good of the whole UK, indeed the world, these efforts must be coordinated and open to sharing good practice and lessons learned, both within Britain and beyond.

We therefore recommend:

1. **Collaboration:** the creation of an active pan-UK cross-sector stakeholder group with support at central and devolved government level to develop and promote a shared agenda for healthcare decision support across the four nations. This should include all the relevant clinical, research and informatics organisations, from the public and private sectors.

2. **Piloting of next-generation decision support** to tackle particular healthcare issues. This should focus on a selection of urgent, specific areas where clinicians can most benefit. This could be because of the volume of knowledge that is frequently updated, where the relevant content from practice guidelines lends itself to becoming computable, where decision support would reduce errors, to enhance safety and quality or where existing decision support is not good enough. Focus in these areas should avoid more controversial areas for decision support where there are doubts about its safety and assurance.

   Pilot projects might, for example, include new or improved decision support for:

   - Ordering laboratory tests in response to patients' symptoms;
   - Optimising the management of long-term conditions;
   - Antibiotic prescribing;
   - Urgent referral guidelines in primary care

Making a shift to computable knowledge and decision support offers great hope (see Appendix for a table of benefits for each of the main stakeholders in health and care). As one NHS clinician explained: "We have an excellent NHS, but it relies on, as always, people within that system caring a lot and then going above and beyond, and doing a lot of manual work, so they become very stressed themselves trying to keep that system going."

A "clinical satnav" – a truly digitally enabled system with a detailed library of medical knowledge properly flowing through it like our car's map - would make practitioners' lives easier. It would make the system itself healthier and more sustainable and would ultimately result in a better standard of care for us all.

Appendix

Some benefits of computable knowledge and decision support for the main stakeholder groups.

Stakeholder Group	Benefit of this approach
Taxpayers and public	A more efficient, safer, evidence-based health and care system
Patients	Safer and faster health care with all parts of the service relying on the same core knowledge
Health professionals	Rapid access to the most recent high-quality health and care knowledge to all parts of a distributed team
NHS Trusts and Health Boards	Safer health care delivered by professionals at all levels following a complete and consistent knowledge base Improves working lives, helping clinical staff build confidence, and providing learning with every experience Lower rates of litigation and staff burnout
Clinical commissioners	Safer, more efficient, evidence-based care delivered by all professionals following a consistent knowledge base
Guidance producers	A simple, fast route to market for their guidance products
Medical publishers and software developers	Access to a common core of health and care knowledge in standard format as a basis for value-added products
Regulators of clinicians, services and devices; courts of law	Easy access to the defined knowledge base of health and care, exactly as it was at the time of a specific incident in the past.
The UK Economy	A new high-value knowledge ecosystem that generates highly skilled jobs and opportunities for innovation, enterprise and global revenue.

This report was commissioned by BCS, The Chartered Institute for IT, and based on interviews with members of a working group on computable knowledge that is organised jointly with the Faculty of Clinical Informatics. The authors were Jack O'Sullivan, Jeremy Wyatt and Philip Scott.