## Turning data into useful knowledge to improve patient care

## Leary A

Every time you shop, take public transport, use energy, access the web though a search engine or send an email you leave behind an invisible footprint in the form of a trail of data. Many organisations such as large retailers collect this data. They want to see how you shop, what you buy, what kind of behaviours you exhibit and if other factors like the weather affect your decisions. They look for patterns in this data and use it to predict how you will shop in future and how they can nudge you into buying a little bit more, or ensuring their logistics chain can deliver goods in time. The data you leave behind is a key feature in helping others understand how you live.

It is often said that data is becoming the oil of the 21<sup>st</sup> century as we have a data driven economy (Rotella 2012). However it's not the data that has value but the intelligence and insight it gives us. That insight will help a major retailer not only run their stores but also make longer term decisions about suppliers, the workforce and its place in the market. As Daniel Keys Moran said "You can have data without information but you can't have information without data"

Turning data into useful knowledge to improve patient care is a challenge for the 21<sup>st</sup> century. In healthcare a huge amount of data is collected and then "warehoused". It sits in data repositories and medical records department s (data can be captured on paper as well as digitally) and it can sit there for years, quietly minding its own business. This is a missed opportunity as that same data may hold the knowledge to improve care, save lives or improve the life of healthcare workers. However very rarely does someone come along to mine this gold.

This lack of use happens for a number of reasons. The way that data is collected and stored often makes it difficult to be useful, particularly to clinicians. Many of the applications in healthcare are designed to capture and store data for review at a later data but not necessarily analyse it. There are also lots of regulatory issues on the use of personal data which are likely to be made more complex with the introduction of The EU General Data Protection Regulation (GDPR) in 2018 which is the most important change in data privacy regulation in 20 years (EUGDPR 2017)

Most organisations keep data in separate applications-for example a hospital might have one data collection tool for incident reporting, one for recording vital signs and others for pathology, medicines and patient administration. They all work differently and collect data in different ways. Most importantly they don't "talk" to each other which mean the chance to use that data to improve care is limited to those with technical skill who can download all of the data, bring it together and analyse it to make it into useful knowledge. This often takes a lot of effort and technical expertise which might not be available in the organisation.

For data to be useful it has to be high quality and the type of data needs to reflect the context of the questions we ask of it. It is not much help if a large supermarket wants to know where and when baked beans are likely to sell by looking at the data about avocados, or plans its supply of ice cream but forgets to look at the weather forecast in doing so.

In England the Five Year Forward view (NHS England 2014) referred to technology as an enabler but healthcare technology and data science is still some way behind other sectors which use data for

intelligence. It's still a developing field and as the largest part of the workforce nursing must play an influential part in its development if we are to ensure patient safety.

Nursing in all its forms is a massive supplier of care and yet looking at the data from healthcare organisations it's hard to see-most of the time the care is not captured and certainly not the complexity of the care. Where data on nursing activity is captured it often massively over simplified. A couple of years ago I was asked to work out how many district nurses were needed for a patch of England. We regularly work out optimum caseloads for groups of specialist nurses and it sounded like an interesting and useful challenge. Optimum caseload calculations are stochastic –it means you have to consider many different scenarios and service models and work out the probabilities of different things happening as this affects workload and therefore how many people are needed. Stochastic models need a lot of high quality data to make them work.

To model a workforce for district nurses the databases they used were accessed and their work downloaded. They used two commonly used commercial packages which record work and are used in the community. Looking at the data revealed that the databases were capturing only a fraction of their work-about 15% of their workload.

Why did this happen? The databases were not designed to capture nursing work. They did not contain nursing interventions just broad lists of tasks and it did not capture the multiple interventions needed (the nurses we looked at did on average six things per visit but the system only captured one). We had to develop a different way of collecting data that more accurately reflected the real world situation (Jackson et al 2015).

This lack of accurate data capture makes it a challenge to show the enormous contribution that nursing makes to care, work out how many nurses are needed, help others understand the complexity of care and how nursing impacts on patient and organisational outcomes like experience, efficiency and safety. If the data is inaccurate, then everything down the line like staffing models or decisions about safety carry that error. A dire consequence is that poor data capture of nursing work means that decision makers make false assumptions about nursing and in particular the risk of things like cost improvement efficiency (Leary et al 2016).

Making decisions based on poor data is sometimes referred to as "garbage in, garbage out" a saying which originates from the early days of mass computing but still holds true today. If the profession allows others to define what they do in data, then we run the risk of losing arguments about value and a powerful voice for the vulnerable.

There is so much potential to improve care by collecting nurse and patient sensitive data. It can be used to calculate workloads and see the value of nursing. It could be used to see where best to use nursing expertise, how to make care safer (for example looking at staffing, vital signs and safety data together).

Being involved in informatics is essential for nursing. Making sure that data captured reflects the real world of nurses, patients and carers is of paramount importance otherwise nursing runs the risk of being invisible in the future.

1039 words

## References

EUGDPR (2017) The EU General Data Protection Regulation (GDPR) <u>https://www.eugdpr.org/eugdpr.org.html</u> accessed Feb 2018

Jackson C, Leadbetter T, Manley K Martin A, Wright T (2015) Making the complexity of community nursing visible: the Cassandra project. *British Journal of Community Nursing* March 2015 Vol 20, No 3

Leary, A and Tomai, B and Swift, A and Woodward, A and Hurst, K (2016) Nurse staffing levels and outcomes - mining the UK national data sets for insight. Int J Health Care Qual Assur. 2017 Apr 18;30(3):235-247. doi: 10.1108/IJHCQA-08-2016-0118.

NHS England (2014) The Five Year Forward View NHS England, London.

Rotella P (2012) Is data the new oil? Forbes Business <u>https://www.forbes.com/sites/perryrotella/2012/04/02/is-data-the-new-oil/#7dc707d17db3</u> accessed Feb 2017