

Data capture, analysis, utility and privacy and a COVID legacy

Our regular readers will be familiar with the concept of the importance of data in the evolution of a wound care specialty. It has been the subject of many editorials and publications with the International Wound Journal over the years. As editors, we felt it important to revisit this considering the recent pandemic years.

The evolution of wound care as a clinical speciality has been slow at best.¹ Many factors influence this including regional differences, but the ultimate clinical aim remains the same.²

Data are essential assets in this journey.³ Sharing of such data is not only important to each patient and clinician but also to the wider clinical community to permit the specialisation of practice. While a multidisciplinary approach is more universally accepted today, the over-protection of the privacy laws regarding patient information, and the current pandemic impacts, have impacted such evolution.

Sharing is caring. Most of our patient's love sharing their story (i.e., data).

Using technology systems such as "apps," clinicians can capture large volumes of data and through sophisticated machine-driven analysis techniques provide the transparency of approach to begin to truly understand the areas of focus and change required to standardise the practice.

Within the past 10 years, we have seen the emergence of apps in a variety of health care arenas, and within the past 5 years, this includes the simple measurement of wound dimensions.⁴ Many of these digital approaches have begun to capture much more wound-related information.

Machine-learning models can be trained to analyse tens of millions of patient records, with billions of data points, something which is impossible for a human clinician as they may only see a few tens of thousands of patients in their entire career.⁴

The capturing, storing and analysing of this vast data collection are not the issues, there are many technological solutions permitting such activities. Society's challenge is the privacy of such vast data silos. Since much of

its pedigree is technological, it exposes such databases to hacking and intrusion.

1 | THE COVID INTRUSION

As the coronavirus pandemic takes its toll globally, both clinically and economically, governments, public-health authorities, companies and individuals have responded with extraordinary measures. To protect collective health, governments and institutions place restrictions on movement and mechanisms for tracking and reporting. These include contact-tracing apps, some recording and transmitting personal health information. The utilisation of such information has exponentially highlighted the importance of data protection and privacy.⁵

Pre-pandemic the advent of the European General Data Protection Regulation, 2018, (GDPR) and similar regional legislations resulted in a growing "ePrivacy Regulation." Governments, companies and institutions as a result became very focussed on their data awareness and security exposures. These new regulations enforce stricter rules on privacy and data protection, setting new standards, for the "rights and freedoms of data subjects" around the globe.⁵

The global pandemic however forced such organisations to take a more balanced approach—protecting public health and protecting personal privacy. The dilemma they faced was that some of the implementations designed to limit the spread of the virus and potentially save lives could also have serious human rights implications, especially around personal data. The very measures implemented to protect citizens could drastically curtail their rights and freedoms.

While many governments measures in these areas are well understood and supported by the affected populations, some concerns are being raised about their intrusiveness on personal privacy and implications for the future. It could be argued that governments have had to change their belief systems and change them quickly. But what does it mean for the future? Will these belief systems remain? Will they only be public health focussed?

As wound carers, we all know that wounds are a significant public health issue. Can we benefit from the change of heart seen during the pandemic?

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