1

Patient Centric Healthcare – What's Stopping Us?

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1.1 The Evolution of Future Health Systems

The primary aim of healthcare systems around the globe is to improve the well-being of populations, with the World Health Organization defining health as "A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (World Health Organisation, 2020). Healthcare is not merely treatments for diseases, it is instead a way to support people to achieve the highest attainable mental and physical and social well-being for themselves. But traditional healthcare systems are not set up in this way, and rather than focusing on integrating all the holistic elements required for promotion of health in an individual, they are orientated toward the treatment of disease and malaise after things have already deteriorated in a person's well-being.

The difference between absence of disease and total well-being is subtle but fundamental. Supporting well-being involves encouraging people to live a healthy lifestyle (both physically and mentally) and providing the tools, systems, and education for each person to aim for the best possible version of themselves often via self-care principles—whether or not they are sick at the current time.

Other factors that have further impacted the tension between the treatment versus a self-care model of health have emerged during the COVID-19 pandemic during 2020, which forced upon us innovations and technologies that were once confined to pilot status. These were mobilized during the 2020 pandemic out of necessity in order to meet the restriction in face-to-face services required to prevent transmission of the virus between people. Many of these rapid accelerations,

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particularly in relation to telehealth visits and remote monitoring, are here to stay because, once pushed to try a new approach, it has been found to be efficient and a positive experience for many (Jones et al., 2020; Norman et al., 2020; Wosik et al., 2020). An area that is a fundamental component of this wave of change is the process of microsampling at home.

For the uninitiated, microsampling involves the taking of small droplet amounts of body fluid—blood or saliva as examples—in the comfort of a person's home. The samples themselves are taken by the patient or with assistance from a caregiver and are then stored and packaged as directed (for example by drying on a specialized sample tip or card and sealing into the envelope provided). These are then either posted or collected and sent to a central laboratory for processing, thus negating the need for a patient to visit an outpatient clinic or local surgery (Bateman, 2020). The laboratory assay must be validated and provide sufficient accuracy to support accurate clinical decision-making. This onset of a remote, patient centric approach to sampling brings with it the chance to fundamentally challenge and change the healthcare delivery model. Sampling and appointments can be decentralized, and most routine supportive care can be virtual. This does not mean the end of the hospital or GP visit, but it does mean that the approach used can be fitted to the requirements of the individuals involved and the healthcare decisions that need to be made. Remote sampling and consultations are more time efficient (Ballester et al., 2018; Prasad et al., 2020; Russo et al., 2016) and this means that not only can they be scheduled around peoples' daily lives better but also any face-to-face appointments can be prioritized for people where in-person consultation is truly needed. For overstretched front-line staff and health systems, this is likely to be a very attractive proposition.

Research has also shown that dried blood spot sampling versus conventional blood sampling conferred cost savings across the ecosystem in renal transplant and hemato-oncology patients (Martial et al., 2016). In this study, switching to home sampling was associated with a societal cost reduction of 43% for hemato-oncology patients and 61% for nephrology patients per blood draw. From a healthcare perspective, costs reduced by 7% for hemato-oncology patients and by 21% for nephrology patients due to the replacement of office-based tests with home-based sampling.

So the evidence suggests that virtual care provides a mostly positive patient experience and is more efficient for the health service. Could this also help reduce the number of people not "turning up" for medical appointment (if the consultation comes to them)? Research has shown that the high levels of "no shows" to hospital appointments have a large impact on the organizational structure and cost to a health provider (Dantas et al., 2018; Jefferson et al., 2019; Mohammadi et al., 2018). Although no research has been carried out on this to date, it is possible that the efficient use of home sampling could reduce this "appointment missing," and this more optimized supportive care for patients could offer

additional benefits on the downstream impacts to service. Another potential benefit of home sampling could be the time freed up for those more in need of face-to-face contact and better decisions on how to balance the two approaches. There are benefits and limitations to both home-based and in clinic approaches—for example, home care approaches which are decentralized have been shown to give better individualized, immediate care, but along with this, the responsibility for monitoring is largely delegated to technical devices, patients, and their families (Oudshoorn, 2009). Face-to-face appointments in the clinic have been shown to be preferred over telemedicine in specific circumstances such as when patients have low self-management ability and/or depending on the purpose of the consultation (e.g. initial discussions about terminal disease, which may have additional, unspoken support needs; Chudner et al., 2019; Derkson et al., 2020). Designing an integrated approach based on the person's needs may be most beneficial for all. For example, in 2019, Jiang and colleagues found that correctly timing a face-to-face consultation increased a patient's ability to accurately find information digitally and administer self-care post consultation. Integrated approaches also bring the potential to save more face-to-face consultation time for personalized conversations and supportive care, leaving more simple tests and interventions to be carried out at home.

The authors suggest the use of home blood sampling may have positive impacts on a person's overall well-being by allowing intrusive interventions to be carried out within a familiar home environment. A survey was taken of 39 adult kidney transplant patients who underwent both traditional venepuncture and microsampling approaches for monitoring of their condition and the current blood sampling burden was quantified using two measures: anxiety and travel requirements (Scuderi et al., 2020). A third of participants ($n = 13$) reported blood test anxiety and 44% ($n = 17$) spent more than an hour just to travel to the required phlebotomy site for standard of care. Preference between the two approaches was also explored: 85% ($n = 33$) preferred microsampling approaches and 95% ($n = 37$) expressed an interest in collecting their microsample themselves at home. This demonstrates a clear patient preference and willingness to give microsampling a go for monitoring post-transplantation recovery progress.

1.2 Exploring the Barriers to Home Sampling

Given the efficiencies and benefits of home-based care, why is not remote patient centric microsampling more rapidly adopted everywhere? The answers may rest with people and the hurdles involved in fundamentally changing established care pathways and healthcare cultures in which people are already working at maximum capacity to deliver what they know, let alone try something new.

The scientific and technological aspects of patient centric microsampling have accelerated in the past 5 years and are driving the field of healthcare in the home; this chapter aims to focus on many of the key concerns that have been heard through working in the clinic, with patients, and developing technologies. The aim is that by starting a discussion around each of these concerns and by proposing potential solutions, developers and leaders of the future will be able to co-create the approaches with the relevant end users and speed up the realization of benefits that these sampling processes can bring.

1.2.1 Barrier One—The Discord Between Innovation and Practice

Recent events of the pandemic in 2020 have shown us that all healthcare systems run at a finite capacity. To implement change, the very same people who rely on established approaches have to, instead, adopt and implement something brand new, while maintaining their high standard of care in challenging times.

The expertise behind the development of highly sensitive microsampling technology has, up until now, been mostly confined to pharmaceutical companies and private laboratories and was generally not widespread in the labs of front-facing healthcare institutions. Furthermore, existing health systems required to implement microsampling systems are built on the fundamental principle *of primum non nocere* (first, do no harm). Sampling and test results are usually only a small part of a clinical pathway, with many healthcare professionals defaulting to the established pathway approaches and more familiar and trusted in-clinic sampling techniques are automatically selected. This involves the deployment of personnel, for example phlebotomists and nurses in a system that, despite being pushed to its limits, is proven to accurately deliver support to clinical decisions. Convenience to patient and family is sometimes seen as of secondary importance, and any potential increase in decision speed is currently unproven with empirical evidence in the standard front-line healthcare systems. It is now commonly recognized that human decision-making usually relies on a System one (fast, reactive, emotional, and habitual) and System two (slower, higher energy, puzzling out a new challenge) approach (Kahneman, 2003). The vast majority of times, human decisions are ultimately based upon responsive, heuristic, and/or emotions, rather than calculated logic—especially when the individual has many years of experience. It is possible, therefore, that emotional rather than rationale drivers may be slowing the uptake of home sampling—for example—trust. For this established and routine model to be replaced, evidence would need to be gathered that the new pathway provides significant improvement in timeliness and physical and/or mental patient well-being. Importantly, overall cost savings for the healthcare system as a whole (primary, secondary, and social care) across the different healthcare models would also need to be demonstrated. Technological advances have the potential to

change elements far beyond use of the device itself—reaching into roles, medic–nurse–patient–carer relationships, behaviors, and healthcare culture and there is understandable caution from front-line decision-makers who are upholding the principle of "do no harm" and have little time to assess the overall healthcare value–benefit versus risk offered by home sampling.

A solution to these problems has been proposed through novel patient centric co-creation and delivery of technology clinical trials that design new or enhanced care pathways with those involved in their routine implementation and then test them empirically in a clinical trial setting. Not only does this mean that the full consequences and potential benefits of an innovation (such as home sampling) that may ripple across the care pathway are considered, but that the proposed ways of leveraging the positives are created by those using the current approach. The subsequent quantitative and qualitative testing of the whole pathway then also provides the empirical evidence as to the impact on people's well-being, ability to deliver the care, and cost. With this approach, barriers preventing uptake are reduced through the intervention design and the drive for change is supported by the robust evidence that healthcare demands (Royle et al., 2021).

1.2.2 Barrier Two—Ethical and Operational Considerations

The ethics involved in home sampling within a new care pathway needs to be thoroughly considered, documented, and discussed with end users before it is put into practice. For example, if the novel innovation is a home sampling test kit then, as well as taking the sample, patients need to accept that they are responsible for taking it. Patients need to store and use the sample kit correctly, dispose of elements in a safe way, and post the sample off in a timely manner. People need to understand why this is necessary and how the data collected from the kit will be communicated to them and what it means—in lay terms. Seamless services are now the norm, but on the odd occasion of a faulty/lost kit, patients should understand how to take action and the provider resolve the problem immediately, so as to maintain both patient and physician confidence in the new system.

There are many areas of healthcare where patients and their families already take responsibility for their own treatment and healthcare. For example, many diabetic patients monitor their own glucose levels and titrate their insulin dose and timings, colorectal cancer screening requires people to send samples for assessment (the affectionately called "poo in the post" screen), all the way through to women taking the responsibility with regard to adherence to the contraceptive pill. The idea that people can take a blood microsample and post it off to a lab should not seem that unusual, and it is logical to assume it will be accepted easily. However, there are very important elements at play in each of these examples. For each, there is a clear and direct benefit for the patient themselves and no "easy"

alternative. Each has also been standard of practice for many years and has therefore become the accepted social norm in many societies—it has long been expected and accepted that diabetic patients and their families monitor their daily treatment and therefore from the point of diagnosis patients inevitably have to accept this role.

For new point of care and home sampling approaches, this "norm" does not exist for both physicians and patients. Even if it makes it slightly easier, the "accepted" and "expected" more traditional approach from all perspectives is for their doctor, nurse, or a trained phlebotomist to undertake sampling. A patient given the opportunity to take on the sampling themselves may, in some cases, compare their minimal professional experience with that of their authority figures. In addition to this, when the microsamples are being used to monitor a specific health condition of themselves or those they love—the consequences of unknowingly getting it wrong become even more worrying.

None of these challenges are insurmountable, but steps should be put in place to develop the care pathway with those involved to ensure that each step—even if it is not one directly related to the mechanics of sampling itself, is considered. In this case, there are several clear elements that can easily help to overcome barriers:

Helpful tips for successful adoption	Description
Making it as pleasant and easy as possible	Simple, quick action. Painless if possible. But also consider the timing and routine. Linking in with habits helps people to remember and make it more "normal" to undertake. Try to avoid additional steps such as intricate assembly or the need to refrigerate.
Recommendation by an authority figure	Conviction that this is the best approach to take, being conveyed and supported by their physician and other trusted healthcare anchors a patient may have.
Building up self-efficacy (i.e., someone's belief that they can successfully do what is needed—in most cases, take the sample)	Time for training and questions built into the process. Having a trusted contact point for help if needed. Share support from peers—other patients who have successfully adopted the system and are willing to volunteer as "champions."
Seeing that it matters—their actions have tangible value	Knowing that the results are to be evaluated and will not be lost (and getting confirmation that they have been looked at).
Having a feeling of control and reducing anxiety	Having an action plan for patients that covers all the main predictable things that may happen (e.g., knowing what to do if the system malfunctions or the sample collection goes wrong). Provide patients with support and help to understand and evaluate findings and what these mean for them.

1.2.3 Barrier Three—Where Does the Liability Sit?

Healthcare workers are always cognizant of their legal and ethical responsibilities to protect the patients they care for and to do this to the best of their ability. But in the case of home sampling, the process is moved out of their control because it is no longer being undertaken by professional healthcare colleagues but by the patient or caregiver themselves. How can professionals deliver to these legal responsibilities if they are not personally carrying out or delegating the sampling to their colleagues that have certificates of training? Where does the final legal liability lie, for example if poor or inadequate sampling results in the wrong decision? This area of law and liability is infrequently discussed, but is one to consider as home sampling and other such services become more prevalent in treatment and care pathways. The Royal College of Nursing in the UK states that "*To discharge the legal duty of care, health care practitioners must act in accordance with the relevant* ***standard*** *of care*." Where the "standard of care" is deemed to be that undertaken by other professionals in a similar situation as a benchmark (Royal College of Nursing, 2020).

Although the legal and ethical requirements which constitute a duty of care to patients may vary across countries, it is important that those who provide and initiate the services of home blood sampling consider their duty of care to patients who may be embarking on a shared or self-care journey. Considerations such as the assessment of the patient and their support network to understand their "health literacy" and capabilities to carry out their tests is an important first step. In addition, a willingness of physicians and nurses to adopt a collaborative shared care approach with patients where support is offered and is gradually decreased as the competence of the patient in this area increases should be evident, in the form of health coaching. In the earlier days of such a culture change, to help build physician–patient trust, this could even mean supplementing the home testing within clinic standard tests at the start of treatment. This would endure until both parties can be confident that the home tests are useful indicators and can be routinely relied on (with in clinic sampling then being for emergency second check only).

Further, the authors believe that the proffering of documented, lay-friendly information coupled with peer support would all allow the physician or nurse to comfortably discharge their duty of care to the patient and caregivers. Indeed, the convenience and possible enhanced quality of life that patients may benefit from is testimony to the ethically robust patient centric decision made within the shared care team.

The authors suggest that standardized protocols for the deployment of home-centered care and sampling would serve to provide guidance, share best practice, and alleviate concerns of healthcare professionals (HCPs). Such a standardized approach in shared care decision-making is discussed by a working party (Elwyn

et al., 2012) with *choice, option, and decision* "talks" described as a robust process to ensure a shared care collaboration between HCPs and patients. Such a model could be developed with a focus on home sampling so that any specific operational aspects can be incorporated and standardized.

Similarly, many patients and families who may be comfortable with the more paternalistic relationship they share with their physician may suddenly see this responsibility of self-sampling as a burden, rather than a release from yet another outpatient visit. This may suggest the need to further support more vulnerable communities if home sampling is to become the norm. In practice, many of these concerns can be addressed early at the point of service design and importantly, in collaboration with all parties, so that appropriate support interventions may be put in place. Indeed, it has been suggested that shared care should evolve such that both physician and patients expect and make room for time to discuss shared options and engage in reflective thinking asking "what if clinicians felt just as comfortable asking questions as providing answers? What if patients were allowed more time on their own to reflect on what their clinician explained?" (Pieterse et al., 2019). If home sampling and other shared and self-care measures are to continue to grow and be deployed in a seamless fashion, then clearly behaviors of all parties may need to evolve.

1.2.4 Barrier Four—Addressing the Technology Challenge

As microsampling becomes more prevalent in care pathways, it is likely to be linked to an increasing number of point of care devices for patients and their families to use themselves. As discussed earlier, with a clear partnership and action plans between the patient/patient's family and their physician comes a huge opportunity for timely action and proactive healthcare. However, it also brings technological challenges, since many patients may be overwhelmed by new technology or instructions that are not available in lay language. Should results be provided via a mobile device, many more mature or vulnerable patients may struggle to "play their part" within the system which could lead to enhanced anxiety and a feeling of exclusion, plus the obvious loss of healthcare data. These challenges are surprisingly not confined to patient populations, since previous unpublished work conducted by the authors highlighted the challenges faced by nursing staff when confronted with a novel Bluetooth device to monitor salbutamol inhaler use in patients with chronic obstructive pulmonary disease (COPD). This eventually led to both patient and nurse confusion when using the device and consequently an associated reduction in adherence.

We also need to consider the *inclusivity* of such new microsampling interventions in the home, since in every country there is a proportion of the population that are not native speakers and may rely upon family, friends, and HCPs for

their care and navigation within that region's healthcare system. Behavioral science underpins the need to not only provide clear, lay friendly information but also reinforce this with using peer support and coaching to highlight the relevance for patients. Clearly, this is of supreme importance in more vulnerable groups who may live on the periphery of our society.

A further consideration is the technological changes that will need to occur in front-line labs, which are currently not kitted out for performing assays on samples derived from patient centric sampling approaches. For decisions to be timely, the performance of the analytical assays must also be. This means that each healthcare institution will need to make a decision—how can they best link with patient centric sampling approaches? Bring the assays in house? Or outsource? This is likely to be different depending on the type of monitoring, decisions made, and relationships that the institute may already have with a third party. Another consideration is which assays to group together. Even though a huge amount of a venepuncture sample may be thrown away, it is still possible to get many standard test results (a panel) out of a single sample. Standard panels have yet to be established for microsampling, simply because it is so new and early adopters usually have bespoke monitoring considerations that they are trying to address.

1.2.5 Barrier Five—The Human Touch

It is clear that a well-designed home sampling service confers many advantages in terms of efficiencies in resource-constrained environments. But for many patients, attending their outpatient appointment is their only chance of human contact with HCPs, and at times, their peers who they meet at regular appointments. Even with the advent of home sampling and virtual appointments which are fast becoming the norm, many physicians can only truly assess patients' whole care needs, in terms of their mental, physical, and social well-being, by seeing them in the flesh where pallor, gait, and general health function can be truly assessed. It is suggested that focused face-to-face visits are planned into a healthcare pathway to complement home sampling, to provide the most rounded care possible. This is especially true for more vulnerable members of society where safeguarding issues may only be truly addressed via face-to-face assessments. Strategic use of new technologies at home may benefit this approach by freeing up time for less rushed and more valued consultations. As identified by Bender et al. (2014), if limited social support and engagement by the medical team is perceived, and self-management requirements increased, this can have a negative impact on a patient's decisional context. With this warning in mind, the role of a more blended care approach, based on the shared decision-making between the physician and patient, again seems optimal.

Other anxieties may perpetuate among the patient community in terms of a fear of bloodletting and of blood itself, and needle phobic people may prefer to remain in a more passive capacity and delegate procedures such as this to others in authority. Noting these concerns, some adaptations to traditional bloodletting are emerging that may help to address some of these barriers, such as on demand blood sampling kits which aim to deliver clinical-grade blood samples with little pain and via simple instructions. How, or if, these will be taken up by different health systems with varying funding options across the world remains to be seen. Clearly, there is a logical need if people want to avoid needles in practice and to support patients so that they may overcome any fears or barriers to home sampling in a patient centric manner.

Not everyone is ready to become an active guardian of their own health. The way in which results are delivered and acted upon by patients in isolation needs to be considered within any patient centric care pathway. Without integration of the home testing into broader engagement and healthcare pathways, patients may feel increased anxiety and isolation in their own homes. This was assessed during an interview-based study conducted by Tiro et al. (2019) in 46 women (median age 55.5 years) who had received a positive home human papillomavirus self-sampling kit result. After reflecting on their experience, six main themes were identified: the convenience of the test, intense emotions after receiving a positive result, the importance of discussing their results with an expert, seeking information themselves from a wide variety of sources; confusion over the meaning and impact of their positive result, and questioning the accuracy of the test. The authors suggest that supportive and interpretative care is available for patients who require assistance while receiving their test results. Further, it is proposed that in extremely vulnerable circumstances, the results are directed primarily toward physicians who would play an active role within the home sampling pathway and results in dissemination.

1.2.6 Barrier Six—Trust in Data Security

For patients and physicians to fully trust a home-based sampling system, any challenges around data security need to be fully addressed at the outset. There have been several incidences of data breaches within healthcare infrastructures (Bai et al., 2017; McLeod & Dolezel, 2018; Seh et al., 2020), and these may contribute to concerns around the security of personal biological data which is sent to a central location. Postal systems can and do encounter problems, and the use of anonymized and encrypted patient codes used to reference biological samples can help to reassure patients of their data privacy and of the resilience of the supply chain from home to laboratory. Patients should be reassured of their data security at the start of their home sampling journey to assuage any concerns.

1.2.7 Barrier 7—Adherence to Service Change

Adherence to any intervention (therapy, treatment, procedure, etc.) is defined by the World Health Organization as "the degree to which the person's behavior corresponds with the agreed recommendations from a health care provider" (Sabaté & Sabaté, 2003).

Despite people being "told what to do for the good of their own health," rates of adherence to recommendations by patients still vary wildly. In developed countries, it has been estimated that around 50% of patients with chronic conditions do not follow their stipulated treatment requirements correctly (Brown & Bussell, 2011; Kvarnström et al., 2018; Naderi et al., 2012). For extremely involved and multifactorial requirements, such as disease management in patients with chronic kidney disease, such nonadherence estimates vary even wider from 3% up to 80% among patients on hemodialysis (Mechta et al., 2018). Failure to adhere to interventions and medications is not simply due to forgetfulness, but to a complex combination of psychological and lifestyle factors, which vary across different conditions. The barriers to the use of home sampling techniques described above opens up an abundance of challenges to adherence, in terms of knowledge, lack of support, and anxiety to name a few. Similarly, physicians and HCPs may express concerns about a patient's ability to carry out their home sampling with adequate competency and adherence, even though the test samples required are small and the process lacks complexity. This said, service providers should aim to integrate both traditional interventions, such as face-to-face clinic visits, alongside home sampling, domiciliary visits by doctors, or use of community pharmacy services. This could be undertaken with a "phased in approach" to allow a patient and caregiver to gain expertise and confidence or "self-efficacy" in their ability to participate actively.

This does not mean that patients suddenly have to become experts in medicine—their healthcare partner can continue to provide this—but it does mean that their observations and support in collecting and acting on the data are equally valued and are a weighted contribution to the clinical picture (rather than considered as useful "supplementary information"). Even at its simplest level, trusting and supporting patients' self-assessments and creating a mechanism to systematically capture and use them can deliver huge benefits. In a randomized controlled trial involving 766 patients with advanced solid tumors, one group received standard of care follow-up, and the other group had standard of care plus an online symptom assessment form that they completed weekly (after email prompt; Basch et al., 2017). Treating physicians received symptom printouts at visits, and nurses received email alerts when participants reported severe or worsening symptoms. Health-related quality of life (HRQL) improved more frequently among participants in the intervention group than usual care (34 vs. 18%) and worsened among

significantly fewer participants (38 vs. 53%; $p = 0.001$). In addition, the mean quality-adjusted overall survival was significantly improved in the intervention group (mean 8.7 vs. 8.0 months, $P = 0.004$) with 75% of the intervention group surviving at 1 year compared with 69% in the standard of care group. The authors draw from this that home sampling could be supported with, for example, internet-based or telephone-based nurse support or indeed advanced peer support, especially at the early stages of home sampling use. Other alternatives could be a phased approach whereby home sampling is punctuated with routine visits to an outpatient clinic as an approach to allow both the patient and physician to grow their confidence in the new model.

1.3 Conclusion: The Changing Role of Home Sampling

The hypothesized *all round* benefits of home sampling are unproven until new care pathways have been objectively tested in the clinical trial setting. But what can be recommended is to design any new care pathway with those involved for maximum patient benefit and ensure that data are gathered to characterize any barriers and alternative solutions that may exist in practice. This detailed knowledge, gathered in practice as real-world evidence, can then be used to drive and share broader patient-involvement approaches to specifically address areas of challenge.

Healthcare has historically had a paternalistic and/or disease-focused culture (Bokhour et al., 2018; Resnik, 2015). In this traditional approach, clinical teams are cast as expert providers, while patients are cast as grateful recipients, with most information exchange occurring when the patient visits their clinician. The advent of home sampling delivers impacts to the healthcare system above and beyond the much-needed upsides of convenience and resource saving. It has the potential to increase the robustness of the data that patients themselves collect iven industries who place their end user or customer at the heart of everything they do, but increasingly, patients are being placed in the driving seat, as the end users and ultimate custodians of healthcare. Growing healthcare costs, a desire for personalized approaches (often facilitated by advancing technologies), along with an increased demand for transparency will continue to drive forward this agenda of co-creation. Home sampling is no exception, and its implementation will further enhance patient centric services which should streamline routine testing and free up more time for more valuable and reflective conversations with physicians at the exact time they are needed most.

Changes that evolved through necessity at the time of writing in 2020 (to avoid face-to-face contact between people during a global pandemic) are here to stay.

With collaboration among the healthcare ecosystem and a willingness to challenge social norms, home sampling can take advantage of the paradigm shifts observed in a year of unprecedented change to become integrated into patient centric pathways of care.

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