PHIN 2021-2025 Strategy consultation

Introduction

PHIN has a very simple agenda: to enable patients to be able to make better-informed choices about their healthcare providers through the provision of comparative information, and to help private providers to demonstrate their quality and continuously improve their care and clinical outcomes. We want to produce good information about private healthcare and see that information used as widely as possible:

- by patients to understand their options, risks and costs when choosing the private healthcare sector, care professionals and providers,
- by healthcare professionals and providers to improve their care and services,
- by policymakers, funders, and others who each play their part in the system.

Every step that brings us closer to those objectives is a positive one.

To deliver on this agenda, we have developed four strategic priorities to guide the next phase of our work: 2021 – 25. We hope to have open engagement with hospitals, consultants, patients, and the sector more broadly about these priorities and their implications.

These four priorities are:

1. **Complete and accelerated delivery of CMA Order**: We will accelerate towards the provision of complete, accessible, high-quality information for patients and healthcare consumers as specified by the CMA, as an essential foundation for progress in any other aspect.

2. **Focus on people's real needs**: We will focus on the delivery of insights to consumers, providing an information service that people find helpful, and promoting our service to ensure that it is better known about and used. Whilst we believe that this is wholly consistent with the CMA's Order, success is likely to require a willingness to go beyond the strict scope of the Order in places, and to challenge our own approach to implementation in others.

3. **Create value for stakeholders**: As well as delivering insight to consumers, we need to build on opportunities to 'add value' to the consultants and hospitals participating in PHIN, and to broader stakeholders including insurers, GPs and the NHS.

4. **Deliver a collaborative and efficient model:** We will continue to pursue the most efficient and effective ways of operating, with the immediate focus being on increased cooperation with the public sector, notably through the Acute Data Alignment Programme, ADAPt.

We hope that all our stakeholders will recognise that our approach is designed, as far as possible, to achieve the best for all concerned.

Below we have provided further detail about each of these priorities, along with a series of consultation questions. Please provide your feedback via the consultation on our website: https://media.phin.org.uk/have-your-say-on-phins-2021-2025-strategy/

Priority 1: Complete and accelerated delivery of the CMA Order:

PHIN was founded in 2012 to begin a journey toward better information for patients. In 2015, it commenced its role as Information Organisation (IO) for the CMA. Its 2015-20 strategy was comprehensive and stretching, planned for compliance with the Order by April 2017.

Progress since 2015 has been solid, but the resource and time required to put in place key elements of delivery (such as data gathering, definition and validation processes) has been significant and progress has been slower than desired. The reality is that the real achievement of the delivery of the Order remains a long way off. To date, we have published only part of the information specified about hospitals, and less about consultants, with the data specified by the Order itself representing only part of the data truly needed to understand activity, performance and value in private healthcare.

For much of the past five years, the main bottlenecks to progress have been in the completeness and quality of the data provided by hospitals, especially the NHS private patient units, and the rate of engagement from consultants. These remain an issue. However, as we have progressed and become fully operational, the scale and capacity of PHIN itself has also slowly become a bottleneck which must now be addressed.

In delivering its duties, PHIN's has needed to develop core competencies in five key areas:

There has been a natural phasing to our work, with much of our collective focus being on ensuring we have 'data in' from hospitals, before being able to shift to providing 'information out' to patients. Hence, our work from 2021-2025 will focus on publishing information and the needs of patients.

The requirements of the CMA's Order were not fully delivered by April 2017 and much remains to be done. Whilst the delays have been understandable, we believe that the timeframe for delivery cannot simply become open-ended. The need for good information from private healthcare has only grown, with the patient safety agenda now taking increasing prominence alongside the original objective of consumer protection.

As such, we believe that complete delivery of the CMA order must remain non-negotiable, and that the private healthcare sector and PHIN collectively must re-commit to delivering those requirements within a realistic but challenging timeframe, and certainly within the life of this new strategy. We suggest that the target date for substantial compliance should be the end of 2023, and note that achieving that will require increased focus, increased resource and some new approaches. That is the heart of this strategy.

The good news is that in achieving that compliance we will also do much of the work required to address the issues raised by the Paterson Inquiry and the Cumberlege Review, and we have the potential to create significant value both for patients and the private healthcare sector.

What 'full delivery' looks like

In our view, full delivery means:

- Publication of all the specified measures that are possible to produce for each recognised procedure at both hospital and consultant level, following transparent methods (noting that some measures such as PROMs are only available for a limited range of procedures, and some measures are only relevant at hospital or consultant level, but not both).
- Fee information published for all consultants covering both self-pay and insured work, but only if hospital pricing can also be published.
- Coverage approaching 100% of both hospitals and consultants involved in private care.
- Full active promotion of PHIN's website as the independent source of information by insurers and consultants.
- General promotion of PHIN's website to ensure consumer awareness and use.

We believe it is important to deliver the full 'intent' of the CMA Order. As such, we believe that complete delivery requires us to publish and market information in a way that consumers know it is there and can effectively use it to make real decisions, i.e., not only that the information exists, but it is meaningfully adopted by consumers. We believe that the CMA intended the creation of this information to serve a real and beneficial purpose, not merely to be brought into existence to show compliance.

Questions:

1. To what extent do you agree full delivery against the CMA Order should be a 'non-negotiable' priority for PHIN?
2. To what extent do you agree that we must strive for real and demonstrable awareness and adoption by consumers?
3. To what extent do you agree that we should aim for complete delivery by the end of 2023

Priority 2: Focus on people's real needs

Over the last few years, the use of the words 'patient' and 'consumer' have often caused concern. In our view, people are both patients and consumers at different stages in their journey. Most people using our website primarily behave like consumers, gathering information to help them make a 'purchase' decision and needing clear, simple information and clear routes to action. By the time they are in front of a doctor, they are patients, expecting to be treated with due professionalism, and reasonably expecting that data will be gathered and used as necessary to keep them safe and protect their interests. This second point was illustrated very clearly by the testimonies of patients given to the Inquiry into the Issues raised by Paterson, and the Independent Medicines and Medical Devices Safety Review (IMMDSR), led by Baroness Cumberlege, both of which were published earlier this year.

Having been appointed by the CMA, our focus has primarily been on supporting consumers in their decision-making, notably in terms of how we present it on our website, and this is increasingly informed by direct market research. However, the information that we produce is equally relevant to protecting patient safety, and we aim to play a full role in providing a positive response to the recommendations of the Paterson Inquiry and Cumberlege Review, as detailed under our 4th strategic priority, below.

Focusing on what is truly needed

To date we have worked very strictly within the scope of the information specified by the CMA in their Order. However, in our view that does not prescribe a perfect and complete set of information either for meeting the needs of consumers or promoting patient safety. Whilst much remains to be done to deliver the basics, we believe that we must also look more broadly at other needs and purposes in parallel.

Our consumer research suggests there are four broad categories of information consumers use when making choices about their healthcare:

1. **Availability**

   Consultant availability and the likely waiting time for appointments and treatment is consistently cited as the most important question for them, and is presumed to be a key differentiator for the private sector. Waiting time information is accessible for NHS services and therefore is an area where the private sector is currently falling short, to its own detriment.

2. **Practicalities & access**

   Consumers place confidence in people over facilities and want to know about consultants, and the experience of other patients like them.

   In terms of facilities, they are equally interested in aspects of service that relate to convenience and practicalities. This may typically include transport, car-parking, accommodation, amenities and other visiting arrangements.

3. **Indicators of performance, safety, and quality of outcomes**

   We need to create a shared view of quality to help consumers understand and trust the data that they see, and to start to build a more general understanding of what matters and why. This is in scope for the CMA order, but a simplified, consistent and shared approach would be beneficial, and we will work with multiple stakeholders to achieve this across the public and private sector.

4. **Price**

   The costs of treatment is a key piece of information for patients, who are funding the cost of their healthcare. We believe it is important to help consumers understand the total likely costs of their procedure and any other associated costs (e.g. diagnostics), in order to make an informed and meaningful choice. Whilst the cost of inpatient treatment and procedures are valuable to understand, they do not represent the full treatment journey. Indeed, many consumers will be facing choices about consultants and hospitals for treatment that may not require inpatient care or surgical interventions.

In terms of patient safety, the Paterson Inquiry and Cumberlege review have clearly shown that information is required on several key areas that are currently out of scope of the CMA's requirements. These include:

- Implantation of medical devices
- Outpatient services and diagnostic testing

We propose to explore how we can best produce and publish the type of information that better meets consumer and patient needs. It may be that enhanced requirements for information to address patient

safety issues will become mandatory in relation to private treatment as well as NHS treatment, and indeed we will advocate for that.

However, in the meantime we can only proceed to properly address consumer and patient needs if the private hospitals, and wider private healthcare sector, support us to do so, by voluntarily providing the additional information needed, and the funding to required to process it.

Rethinking our approach to some elements of the Order

Previously, we have spoken about our intention to be guided by the 'intent', rather than 'letter' of the CMA Order. To do this we believe it is necessary to rethink our approach to some elements of the Order. There are three areas in which an alternative approach may deliver information which is going to improve decision-making for consumers:

- **Fees and prices**
  We firmly believe in pricing transparency. The provision of consultation fee information is an important guide to patients seeking a consultation to seek or confirm a diagnosis. However, we must also recognise that the private healthcare market has moved on since the CMA's investigation report in 2014. Where consultant's procedure fees were identified as the missing part of costs, pricing has moved on – most notably with the wide-spread adoption of self-pay package pricing for both self-pay and insured customers. We therefore believe that in the current climate it may now be unhelpful, and potentially even misleading, to publish consultant fees in isolation as it presents an incomplete picture of the costs involved to treat a particular procedure/consumer need.

  The only way the sector can really signal transparency and openness to consumers is to publish complete, fully comparable pricing information, and this was the intent of the CMA's report. As an interim solution, the CMA has asked us to explore obtaining details of hospitals' package pricing from the consultant. However, a truly comprehensive solution would be to work with providers to develop a common pricing architecture and definitions around how prices are made up, a common taxonomy for terms and conditions.

  Ultimately, if our aim is to publish complete and meaningful price information for patients including hospital prices, it may make sense to cease the publication of consultant procedure fees in isolation to avoid actively misleading patients and continue only with their consultation fees

- **Patient Reported Outcome Measures (PROMs)**
  We believe that PROMs can play a transformative role in the interaction between patients and consultants, as well as supporting consumers to make decisions based on the experiences of others. Data is beginning to flow, and in 2019 we published the first basic outcome measures for private healthcare, in relation to hip and knee replacements. We welcome the support for PROMs shown by the Cumberlege review, which may lead to suggestions or even national requirements to add further measures into scope, notably in relation to the treatment of stress urinary incontinence.

  However, many providers tell us that have struggled to implement PROMs effectively, and patient response rates in private healthcare remain well behind those seen in the NHS. This is perhaps doubly surprising given that people have paid significant sums of money for an outcome. Additionally, the Q-PROMs measures for cosmetic surgery, originally specified by the Royal College of Surgeons in England in response to the Poly Implant Prostheses (PIP) scandal have received little practical support since their launch in 2016. The consequence is that PHIN has received too little data to produce publishable information on most of the covered procedures so far.

In early 2021 we plan to review how we collect and present PROMs data, seeking to identify and address the factors that have inhibited progress and limited patient engagement in the actual outcomes of their treatment. Currently our intention is to keep a similar range of procedures and measures to that already in scope, while recognising sensible suggestions for change (substitution) of more relevant procedures and measures where appropriate, as we have in the past.

- **Consultant performance measures**
  Two years after we first published performance measures for consultants, around 2,500 consultants, or fewer than 20%, have validated their performance data for publication. We believe that it is right to give consultants the opportunity to validate data and have any data errors corrected by hospitals prior to publication. We have created a system to facilitate that process which we continue to improve. Our approach has been that no data is published unless and until a consultant has chosen to log in and validate it – effectively an 'opt-in' model. However, the rate of progress toward full publication is clearly too slow, and we need to consider alternatives. Our current thinking is that it might be time to shift to a 'time-limited opt-out' model, where a reasonable period of time is given for consultants to engage and address issues, after which the data is then published by default unless the consultant has informed us of underlying issues with the accuracy of the data and identified actions being taken to address those issues. This would place the onus firmly on consultants and the hospitals at which they practise to ensure that their data is accurate in a timely fashion, consistent with the CMA's Order. The precise mechanism will need careful discussion and design.

Questions:

4. To what extent do you agree that PHIN should deliver a website which provides a more comprehensive suite of information to patients, some of which may sit outside of the scope of the CMA Order? For example: consultant availability or hospital amenities.
5. To what extent do you agree that PHIN should be producing information focused on clinical and governance improvement to support patient safety initiatives, addressing for example the issues raised by the Paterson Inquiry and Cumberlege Review?
6. To what extent do you agree that PHIN should cease the publication of consultant procedure fees in isolation, if a broader agreement can be found on publishing more complete pricing – including package prices and diagnostic costs?
7. To what extent do you think that collecting a broad range of outcome measures based on patients' own structured assessment of their outcomes (PROMs) remains vital?
8. To what extent do you agree that PHIN should shift from an 'opt-in' process for publishing consultant activity, to an 'opt-out' process where the default expectation is that information should be published unless the consultant has signalled underlying issues with the accuracy of their data?

Priority 3: Create value for stakeholders

PHIN has created and will continue to create assets in such forms as data capture, data flows, relationships and ways of working with consultants and a varied and large number of private hospitals and PPUs, as well as the data sets themselves. These have value – both clinical and potentially financial.

Currently our funding is based on a 'compliance' basis. i.e. we have only sought funding to fulfil our mandate under the Order. However, there is much that PHIN can and wants to achieve in line with its purpose, as discussed throughout this paper, which will directly benefit patients and consumers. To achieve that we believe greater resources are necessary.

It is important to note the strict limits of our ambition: as a not-for-profit entity, PHIN itself cannot "make money". However, additional income could help us to accelerate the delivery of the Order and do more work to deliver value to patients faster, and/or could potentially help offset some of the cost burden that falls on private hospitals, which is ultimately borne by patients in fees or insurance premiums.

There are a number of ways we can create value for participants and stakeholders:

1. **Information and insights provided to market participants**

   The capabilities PHIN has developed and its positioning as an independent and 'honest broker' in the system can be deployed to deliver value-creating propositions and market insight for members and other sector players.

   PHIN's role involves producing information – as intended by the Order. In doing so, we clearly can and do create a whole range of related information, and that has value in a wide number of applications.

   We believe that some of those applications have real benefit to patients, even if indirect: information for GPs, for employers operating private medical schemes, for insurers, for policymakers, for regulators, for assisting public inquiries, for academic study to increase understanding, and so on will all bring benefit back to patients. Currently we are only able to pursue a handful of those opportunities.

   This might include the delivery of national and regional market insight to providers, directories of practicing providers and consultants (in which consultants normally pay to participate), or anonymised benchmarking reports for specific procedures or geographies. It might include tailored materials for GP practices highlighting private healthcare in the area. We could also make our collated information available for syndication: be that to hospitals, insurers or consultants to display independent, validated information on their own websites.

   We have long held the vision that PHIN would become a genuine shared resource for the private healthcare sector, ensuring that accurate and complete information on private healthcare performance (without any transfer of personal data) was available across the system. The investment has already been made to create a comprehensive dataset and the governance to handle sensitive data appropriately. A shared resource would improve clinical governance (in line with the Paterson Inquiry recommendations), planning, fairness (especially to consultants who are frequently assessed by insurers based on available data rather than the complete picture), and – we believe – competition.

2. Information platforms

In performing its core duties, PHIN has created assets and capabilities in governance, technology, and other areas which can be developed to create value beyond the fulfilment of the CMA's Order.

This is perhaps best illustrated by the present example of IHPN's proposed Consultant Information Sharing System (CISS), part of the sector's response to the issues raised by Paterson. This service has a strong connection to what we do (bringing transparency in the pursuit of patient safety), builds on the relationships we have (with providers and consultants), necessitates robust governance, and demands a system for collecting information from hospitals and consultants for sharing and publication. We have all of those assets, and believe we are well placed to contribute to such initiatives. In doing so providers would not be required to pay again to build something that is largely already there.

3. Release value from the underlying data – sharing a unique asset for the right reasons

In this section we refer to data as the underlying, potentially identifiable episode-level data that we hold, rather than the information that we produce from it. This is an area that we discuss with some caution, as there is (rightly) great concern at any notion of "selling data". We have no intention of whatsoever of selling the patient-level data that we hold, and it would be illegal to do so for commercial purposes, potentially incurring substantial fines not just for PHIN but for the private hospitals from which data originates.

However, it is helpful to recognise that the data we have assembled can serve many legitimate purposes. We must fully consider and understand the circumstances in which data sharing is both desirable and appropriate – for example, to support research and initiatives to drive clinical improvement, and what the implications would be in terms of value.

The NHS routinely makes data available to third parties for research and other purposes, applying a rigorous governance process to ensure that each specific instance of data sharing is lawful and appropriate. Some of those third parties are commercial organisations, but the uses to which the data are put must still assessed as having tangible benefit to patients and healthcare. The only fees charged are calculated to cover the costs of preparing the data. The NHS is increasingly recognising that healthcare will progress much faster where data can be made available for research and development in a responsible way and is getting ever better at doing so.

Our assessment is that, by comparison, private healthcare in the UK is far behind: data is not generally made available to support research, while technology and information processes are generally regarded as costs rather than assets. Currently, PHIN does not have extensive data sharing agreements with third-parties, and does therefore not seek cost-recovery for sharing data.

PHIN does not propose to go down this route. Indeed, PHIN's current trajectory will see us hand over significant control of our data to national authorities through the Acute Data Alignment Programme (ADAPt). This will effectively contribute the private data into the national dataset, to be held and distributed by NHS Digital on the same basis as the NHS episode data, and hand the asset and its value to the state. We would potentially have the option to restrict the uses to which the privately held episode data could be put under contract, but PHIN will no longer have full control of these data and would not be able to off-set the costs of data preparation through cost-recovery, as is the case in the NHS.

PHIN believes that is the right thing to do, as sharing will ensure that private episode data becomes available to be included in research and all the other beneficial purposes set out as the rationale for

ADAPt. We believe this offers by far the biggest available benefit to providers and all other stakeholders including patients, but in the short term there is a trade-off of control.

We note some of the concerns raised to PHIN about sharing data with commercial entities. Professional associations have suggested that there should never be any sharing of PHIN's data with commercial organisations. We recognise and share the underlying concern but are wary of the formulation. For example, if drawn too broadly, it could preclude the sharing of data for legitimate research. We see ADAPt as a potentially the best route for this: given that NHS Digital has created robust data release processes deemed fit for NHS patient data, it seems sensible to work through that process rather than recreate our own.

4. A transparent market is a healthy market

We believe that the greatest value PHIN can bring for its members and other stakeholders, is simply to do our job well. PHIN's primary focus will always be in service of patients. While we work alongside private healthcare providers – both independent and NHS Private Patient Units, and closely with consultants and insurers – we must remain staunchly independent as an 'honest broker' and demonstrate total transparency.

That said, we also believe that a transparent market will ultimately be a healthier market. The work we are undertaking to aid consumer decision-making will we believe build confidence in the sector as a transparent, consumer and patient-oriented, and open. Transparent information shines a light on performance and gives an opportunity to showcase the quality to those undecided about the best provider for their care. In addition, the political and public discourse about private provision will be increasingly informed by real information, insights and patient experiences.

To be effective in highlighting the quality that exists within the sector, PHIN will have to place more emphasis on promotion with patients and consumers – potentially placing us in competition with providers of care. A good example of this is with digital advertising, where the private healthcare providers currently compete for keywords and listings. To effectively highlight the quality that exists within the sector, and build confidence in it as a transparent, patient-orientated market, PHIN will need to focus greater energy competing in these areas.

In the future we would hope that instead of providers competing for a high-ranking based on spend with Google, they would rather prioritise a high ranking based on performance and value on PHIN's website and support the promotion of PHIN's website

Questions

9. To what extent do you agree that PHIN should look to provide information and insights back to providers submitting the underlying data?
10. To what extent do you agree that PHIN should be providing information and insights to broader stakeholders, including consultants, consultant representative groups, responsible officers, GPs, commissioners (PMIs), and regulators such as the GMC and CQC?
11. To what extent do you agree that PHIN should exploit additional use or value of our information systems?

12. To what extent do you agree that PHIN should aim to relinquish control over its private healthcare data (an asset with quantifiable value) to NHS Digital via the ADAPt programme?
13. To what extent do you agree that PHIN should devote greater resources to marketing and promotion of our website?
14. Are there any other ways you believe PHIN could create value for stakeholders?

Priority 4: Pursue collaboration and system efficiency

We are seeking to reduce effort, duplication and barriers across the system for all, not just optimising for PHIN's operating model and cost base.

Agreed standards and definitions benefit consumers as we develop a common way to view and understand information. Having fewer data submissions and systems to interface with also provides benefit to providers through reduced repetition and effort.

It is our intention to further develop partnerships, including with the public sector, private sector, and third sector (e.g. patient groups) and considering what capability it may be more efficient to outsource or co-produce.

Putting cooperation with the public sector at the heart of what we do

Over the last few years there have been prominent examples where the lack of cooperation between the private sector and NHS has led to patient harm – most notably the case of Ian Paterson. This alone highlights the importance of putting collaboration and a shared public-private data set at the heart of any future strategy for PHIN and the private healthcare sector.

PHIN seeks to do this by:

- using our unique expertise and understanding of the private clinical healthcare data to support broader initiatives to improve patient safety, for example, working with Getting It Right First Time Programme (GIRFT) and the National Clinical Information Processes (NCIP) in response to the Paterson Inquiry.
- collaborating with and supporting independent and NHS efforts to align systems to collect and publish information about healthcare and improve efficiency.

We plan to continue our endeavours to work NHS Digital on the ADAPt programme to adopt common standards for healthcare measures. This is primarily to help achieve our desired outcome of enabling transparency and patient choice; but also in an effort to improve the system we work within.

Under ADAPt, it is envisaged that all private hospitals will soon submit the data mandated by the CMA to NHS Digital in compliance with NHS Information Processes. A public consultation on the pilot stages of ADAPt concluded in May 2020, with overwhelmingly positive support from a range of concerned organisations and individuals.

Questions

15. To what extent do you feel should PHIN seek to support broader initiatives to improve patient safety and collaborate with the NHS to support efforts to align systems?

Funding over the coming 5 years

As a purpose-driven entity, PHIN will prioritise the achievement of its objectives above its own longevity; PHIN exists to serve a purpose, rather than for the sake of existing. We know that a wide variety of organisations are enthusiastic about our agenda, which could potentially pose opportunities for funding and investment for the future, while also posing challenges.

Over time, we might need to ask ourselves whether we are open to widely different futures: from one extreme of inviting others' active participation in PHIN in pursuit of patient / consumer impact and widen investment from outside the immediate sector players; to another extreme of the folding of PHIN's agenda into an entity that is better placed to pursue a system wide agenda.

The CMA placed the obligation on private hospitals to fund the 'reasonable costs' of PHIN's work, and their subscriptions, in strict proportion to activity, have provided all of our income to date. It is understandable that the private hospitals who bear the cost of compliance with the CMA's requirements urge PHIN to keep its costs down, and we have.

However, more will be needed to deliver those first two strategic priorities of delivering essential information in a reasonable timescale, and to do so to a standard that makes it meaningful for patients. In line with the CMA Order, the pursuit of these priorities will be funded through the fees from providers, unless another viable approach can be agreed. We proposed no material increase in fees for our financial year August 2020 - July 2021 but will enter into discussion with members and providers over the coming months to agree an approach to funding from August 2021 onwards.

Priority 3 (Create value for sector players) opens up the potential for increased investment from a wider range of sector players in return for new products and services. As well as delivering value for the sector, some of these models would also increase the diversity of funding that PHIN receives and ensure that not all of PHIN's resources have to be delivered through increasing membership fees.

Whilst the basic capabilities and infrastructure are in place, there would be a level of investment in additional capacity needed to pursue these ambitions. Commercial models could include paying for individual services for those who will benefit; or a set of services available for all members in a refined and more value-adding membership model.

Our commitment in Priority 4 (Deliver a collaborative and efficient model) will focus on the best model of delivery for all, and not just for PHIN. This may change the requirement for PHIN's direct funding over time, as it works increasingly in partnership with others and focuses its role and resources accordingly.

Of course, it is important to note that any changes to PHIN's funding models cannot come at expense of our independence and credibility.

Questions

16. To what extent do you agree that PHIN should review fees paid by providers (in line with the Order) to ensure full delivery of the Order in a quicker timeframe?

17. To what extent would you agree that PHIN should explore additional revenue avenues to create greater value for stakeholders, for example, explore a 'value-adding' membership model based on additional insights for broader stakeholders such as GPs?

Closing Question

18. Do you feel that there are other issues PHIN should be considering and giving priority in developing their strategy for the next five years?