New South Wales

Special Commission of Inquiry into Healthcare Funding

Submission Number:	176
Name:	Consumer Leaders in Health Collective
Date Received:	17/11/2023

Special Commission of Inquiry into Healthcare Funding in NSW

Submission: Consumer Leaders in Health Collective, November 2023

This submission is from the NSW Consumer Leaders in Health Collective

Membership includes experienced, seasoned consumer representatives who individually work with NSW Health across the State in system and service design. Initially brought together in 2021 to provide feedback on the NSW Health Future Health Strategy, individuals continued to meet and collaborate and formed the Consumer Leaders in Health Collective. The Collective also benefits from the membership, participation and contribution of Health Consumers NSW. Members include:

Adam Johnston
Anthony Brown
Brad Rossiter
Craig Cooper
Harry Iles-Mann
Helen Belcher
Ian Duffield
Ian Hoffman
Jacqui Fahey
Jacqui Forst
Jan Mumford
Jill McGovern
Jo Spicer
John Hayden
John Stubbs
Kate Bowles
Kelly Foran
Laila Hallam
Margo Hoekstra
Matt Roger
Michael Morris
Tara less
Tricia Parker
Zoe Fernance

The views expressed in this submission are the views of the members and do not represent the views of any of the organisations they may also be associated with.

The Collective also supports the Health Consumer NSW submission into this Special Commission of Inquiry.

Consumer representatives enable patient partnerships

Experienced consumer representatives are health service users who either live or have lived with significant illness or injury, or who have cared for others living with illness or injury. They draw on their own personal experiences and those of others to identify, explore, understand and problem-solve the complex health issues faced by healthcare service users. Through participation in health system processes, committees, projects and strategic planning, they are also informed observers of system funding and governance challenges.

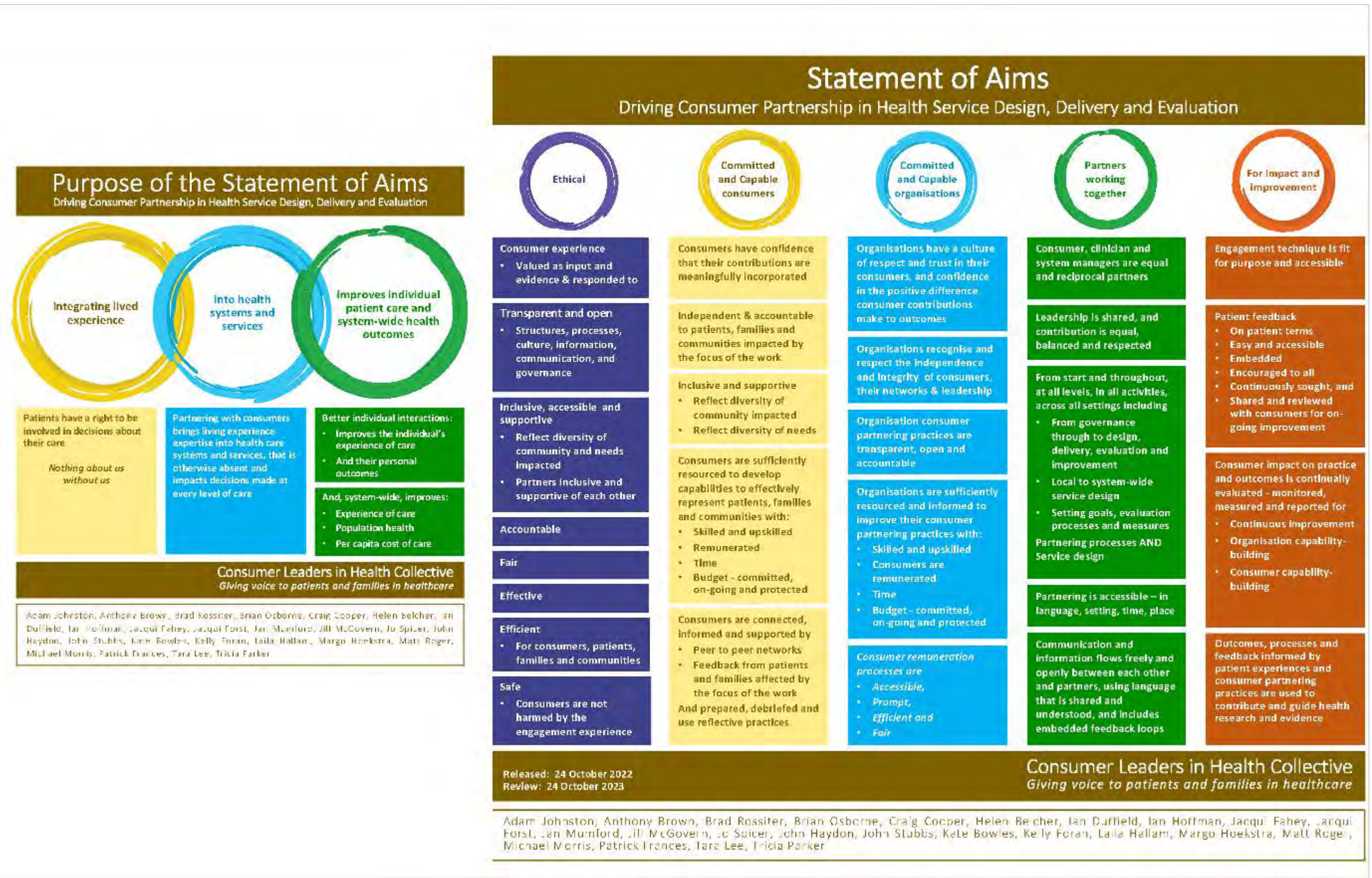
Right care in the right place at the right time the first time - IS efficient care

Our objective in this submission is to question how current funding models, and how services are operationalised, incentivise health systems in NSW to deliver services that meet the needs and expectations of the service users and communities they are designed to serve - safely, effectively, efficiently and equitably, and in accordance with the requirements of the Australian Commission on Safety and Quality in Health Care. Quality care is providing the right care in the right place at the right time the first time that meets the needs of the service users and communities they serve.

Recommendation

To this end, we recommend that at the most fundamental level, the lived experience of consumer representatives and consumer leaders should not only be embraced as critical stakeholders in the governance of safety and quality, but also in allocation and governance in relation to funding as equal stakeholders equal with clinical and system manager stakeholders. Without the guidance and insights of those who experience the impact of funding system priorities will continue to overlook and introduce unintended consequences in the quality of patient care and community wellbeing.

Over 18 months, the Collective developed The Statement of Aims to activate consumer representation to partner with clinical and system manager stakeholders to prioritise, design, implement and evaluate health systems and services to enable effective patients as partners in their own care, to the extent that they choose, as required by Standard 2. See below and Attachment 1.



Purpose of the Statement of Aims
Driving Consumer Partnership in Health Service Design, Delivery and Evaluation

Patients have a right to be involved in decisions about their care

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- Valued as input and evidence & responded to

Transparent and open
- Structures, processes, culture, information, communication, and governance

Inclusive, accessible and supportive
- Reflect diversity of community and needs impacted
- Partners inclusive and supportive of each other

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Fair

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- For consumers, patients, families and communities

Safe
- Consumers are not harmed by the engagement experience

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Consumers have confidence that their contributions are meaningfully incorporated

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- Reflect diversity of community impacted
- Reflect diversity of needs

Consumers are sufficiently resourced to develop capabilities to effectively represent patients, families and communities with:
- Skilled and upskilled
- Remunerated
- Time
- Budget - committed, on-going and protected

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- *Accessible,*
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Identifying current priorities: Follow the money

National Activity Based Funding (ABF)

Activity Based Funding is a model jointly funded between the Commonwealth and State and Territory Governments under the National Health Reform Agreement of August 2011 and was most recently revised under the 2020-25 Addendum to National Health Reform Agreement.

The Commonwealth and State and Territory Government pool their contributions, and then re-allocate across the States and Territories, and then in NSW by LHDs, Ministry and specialty services. The main funding pool is complemented by Block Funding (supporting small rural hospitals, non-admitted mental health services, sub-acute service, training and research and other specialised services) and Cross Border Funding. Nationally, total payments into the pool of Activity Based Funding grew from $32b in 2012-13 to $59b in 2022-23, an 87% growth over 10 years; while NSW expenditure receipts went from $12.5b in 2012-13 to 16b in 2022-23, a growth of 28%.

Understanding whether this is an efficient use of funds is almost impossible to determine without the transparency to follow the funding from its source to how it is spent in individual services.

Using funding levers to incentivise safe, high quality care

In 2017 amendments were made to the Activity Based Funding model to link organisational funding with the performance of services to meet The National Safety and Quality Health Service (NSQHS) Standards. Has the funding model been evaluated against safety and quality measures and patient care outcome improvements?

The complexity of Activity Based Funding, along with the lack of granular transparency in how it is allocated, is not conducive to evaluating its performance community and service user needs and safety and quality measures.

Using funding levers to prioritise research gaps and encourage practice to follow the evidence

Prioritise funding on research into severe life-limiting and debilitating illness, with the long term goal of breaking the cycle of disease-driven social disadvantage into the future.

Focus research on emerging areas, evidence gaps and new knowledge, including patient-side research, so research effort is less risk averse, more collaborative, and encouraged to broaden into less known areas.

Incentivise and reward services that incorporate best and emerging evidence into their practices. Effective care reduces waste and is efficient care.

Using funding levers to adapt to future population changes and needs

As the Australian population continues to age, so too will they be impacted by high rates of chronic illness, and become more dependent on health services. The nature of their needs will shift, and potentially surge. Health services will have no choice but to shift and adapt if they are to continue to deliver the services its population needs now and in the years ahead.

At the same time as this changing and potential surge in the nature and demand of health services, is the reduced proportion of taxpayers left in the pool to generate the income required as more of the population enter retirement. It will leave fewer taxpayers in the pool to shoulder and generate the income required to sustain older, ageing population.

As well, there are the challenges created by climate change. From the changing nature of population needs, including the impact of extreme heat-related illnesses as temperatures soar. To re-imagining and re-engineering the health industry to minimise its impact on the environment and climate change.

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How is the Activity Based Funding model incentivising the changes required to face these realities?

Using funding levers to incentivise equitable care

Following the recent submissions and report into the Health outcomes and access to health and hospital services in rural, regional and remote New South Wales, 2022, the metropolitan and non-metropolitan divide in the provision of healthcare services is evidence that the model is allocating funds equitably.

Further, do peer hospitals have comparable resources to deliver comparable core services? This is of particular relevance to regional and rural hospitals to ensure they have the staff and diagnostic and other resources they need to assess patients presenting to hospitals.

This is magnified when faced with local time-critical crisis events that require rapid assessments, such as workplace accidents or car accidents. What should the community expect from its local services, particularly relevant outside of metropolitan areas in regional, rural and remote areas?

It also applies in birthing care, which is key to the long-term health of the infant and mother. Are costs being saved at the source, that are then creating multiplied and potentially preventable expenditure downstream?

Using funding levers to minimise the cost burden

Do the administration costs associated with Activity Based Funding make sense? There are explicit costs associated with the involvement of State and Territory government oversight as well as three organisations at the Commonwealth level: the Independent Hospital Pricing Authority, the National Health Funding Body, and the Administrator of the National Health Funding Pool.

Then there are the hidden administrative costs associated with coding the service delivered to receive payment.

The ABF requirement involves assessment via a coding regime at the individual patient level. Increasing comorbidities increase the "value" of the patient for payment, but also increase the complexity of diagnosis. To receive the full ABF payment for the patient interaction, the health service must accurately code the patient's diagnosis. This requires both diagnostic equipment, as well as doctors and ward clerks available and skilled to accurately code the patient interaction, without which health services are not being properly re-imbursed, and remain in a cycle of chronic under-funding.

> *"In summary, using ABF for funding hospital services devolves responsibility to each clinician, in each clinical unit to document all treatment and movement of patients while they are in hospital, so that the full cost of their care is captured."*
>
> *Jeanette Sheridan Thesis: 'Activity Based Funding: The Basis for Australian Health Policy'*

For more information on the Activity Based Funding, please refer to Jill McGovern's separate submission to this Special Commission on healthcare funding.

Are system and service cost savings simply being transferred to patients – hidden and unreported?

While patients wait for hours to support the 'efficient' running of a clinic, they are losing time, income, and often incurring costs to have others cover for them in their absence. Patients and communities who live at a distance from major health services incur additional costs of travel and accommodation, extended family care, and more substantial time off work. They also face the additional emotional cost of receiving treatment without the support of family and friends who encourage and support quicker healing and recovery.

Regular service users are often required to attend unnecessarily more frequently simply to cater to the agenda of the services, rather than consolidating the appointments for the convenience of patients.

Is it fair and reasonable that services can be considered 'efficient' when they run at significant cost to their patients and families?

This is exacerbated exponentially for people who live remotely from hospitals in NSW. The cost is considerable for private individuals, hospital ambulances and people who are chronically ill and require regular care. Technology has delivered improvements to services and facilities in cities, exposing many regional patients to additional costs and travel. This is exacerbated with many regional and rural hospitals having lost key operational capabilities such as operating theatres, medical imaging, birthing, blood transfusions, dedicated resident medical practitioners, mental health services, oncology, diabetes, and dialysis. For Virtual Care modalities to enable better care, patients will continue to need the support of local resources.

Honing in on NSW

How services are organised: Decentralised Local Health District model

In NSW there are 15 Local Health Districts, each with duplicated governance, design, delivery and evaluation structures.

Is this a quality-driven organisation of services designed to deliver patient-centred, safe, high-quality, healthcare consistently across the State? Does the duplication of structures across 15 LHDs deliver the patient care gains that partner with patients to minimise error, minimise preventable readmissions, and provide the right care in the right place at the right time, the first time, anywhere in the State for optimal patient outcomes? If so, it will also be efficient. Effective care is efficient care. If not, it should be reconsidered. Either way, it must be periodically and regularly evaluated transparently to ensure it is delivering to the standard agreed to by patients, communities, clinicians and system managers.

Disconnected funding that is disconnecting primary, secondary and tertiary care

How are the funding models using their combined leverage to deliver co-ordinated, integrated, holistic patient care, across care settings, and in line with patient preferences? This extends to patient information sharing, access to patient records, the needlessly wasted appointments (time and cost) patients are forced to attend on a one-on-one basis to suit services, rather than fewer, better co-ordinated and multi-disciplinary appointments catering around patient needs, while wasting less time.

If we consider how long these issues have been known for, and remain current still today, then progress is excruciatingly slow. Is this good enough?

Patients and families as passive recipients of care

This fundamental view of patients is a deeply entrenched and enduring bias that is embedded into services and filters into patient care interactions. Hospital care, in particular, is designed around passive patients while spruiking the need for patients to be more ‘active in their care’. However, this is a fallacy. People living with illnesses self-care and self-manage every day they are not in hospital facilities. There is ample evidence that supports that patients and families who are active in their care are also more likely to be safe while in hospital, have shorter stays, are more engaged in their treatments and care, are better detectors of their deteriorating health and intervene earlier, and have better patient and clinical outcomes and better quality of life. That also means their involvement in their care is more efficient care.

An example of an immediate opportunity: Let food be thy medicine

(Patient testimonials and photographs provided by Harry Iles-Mann, Consumer Leader and Health Strategy Consultant)

Staffing and clinical procedures

> *Having spent over 40 weeks admitted to a specialty transplant ward in a major metro public hospital, it was a continued point of frustration that simple clinical tasks (eg. cannulation) would take multiple hours to be completed. This was due to few nurses having relevant accreditation for specific and specialised tasks despite working almost exclusively on a specialty ward. It was not uncommon for me to wait for 3+ hours for tasks like cannulation as the only hospital staff accredited to perform the task after hours were the (comparative to inpatient numbers) few medical registrars - ultimately delaying the infusion of medication and impacting negatively on mine, and others' health and wellbeing.*

Outsourcing, malnutrition and food wastage

In 2009, it was revealed that the roughly 22 million meals served to patients every year contained only $4 worth of food and drink (https://www.dailytelegraph.com.au/how-nsw-spends-4-on-patients-food/news-story/5fcd810fcd7ffcb918eabf5dbe048aa2). Patient meals are no longer prepared in-house in hospital kitchens. Instead they are contracted out to food services which then deliver cooked-frozen meals to hospitals. These are then reheated and served to patients. In 2009, this meant costs of $7.34 to get a meal to a patient, compared to the $4 worth of food itself (https://www.dailytelegraph.com.au/how-nsw-spends-4-on-patients-food/news-story/5fcd810fcd7ffcb918eabf5dbe048aa2).

At the time of this finding, nutrition experts recognized good nutrition as key to patient recovery, health, and wellbeing. Despite this, in 2021, 40% of patients in NSW Public Hospitals were still malnourished - resulting in an estimated additional cost to the health system of $44,175 per hospitalization.[1]

The visual quality of meals contributes to the problem.

Having been hospitalized twice following liver transplant for a total of 40 weeks, I observe that meals are diverse and varied in only their capacity to disgust and revolt. This often resulted in meals being collected untouched, and then disposed of.

Not only is this having a negative impact on patient health and experiences of care, but the fact that food is being left uneaten suggests a major contribution to food waste, despite NSW Health's commitment to sustainable health care.

There is also a significant overuse of single use plastics on food stuffs (often fresh skin fruit) that don't sensibly require it, as pictured …

The combined financial cost to the NSW Government of statewide malnutrition and environmental impacts that have resulted from outsourcing meal services in

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[1] https://www.heti.nsw.gov.au/__data/assets/pdf_file/0019/703009/FISHER,-Erin-Final-report.pdf

public hospitals is excessive. The decision to outsource meal preparation and strip hospital kitchens of the capacity to do more than reheat meals, while initially appealing as a cost saving, has delivered poorer health, experiential, environmental, and financial outcomes for the State of NSW and its population.

Bringing it together

The goal should be to reduce the need for patients to attend hospitals unnecessarily by investing in well-designed, patient-centred, accessible, available and properly resourced primary and community care.

Is the decentralised service delivery model generating substantial and consistently high quality, patient-centred care (as identified by service users and communities) across the State?

In 2017 amendments were made to the Activity Based Funding model to link organisational funding with performance of **The National Safety and Quality Health Service (NSQHS) Standards**. Has this been evaluated to determine how it has improved safety and quality measures and patient care outcomes?

This Special Inquiry is one of a few very recent reviews that reach into the delivery of healthcare in Australia and in NSW. These include:

- Health outcomes and access to health and hospital services in rural, regional and remote New South Wales, 2022
- The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 2023, which also delved into the experiences of people in our health systems;
- The Royal Commission into Aged care Quality and Safety, 2021
- And now this Special Commission of Inquiry into Healthcare Funding in NSW

Highlighted is the common and overwhelming theme of disconnection between service users, communities and health services. The disconnections are arising continuously across care settings and across time. Is it time to reconsider how these issues are being addressed?

How are systems prioritising, designing and evaluating their services to genuinely meet the needs of service users and communities, and enable active patient partnering to the level they choose, in every interaction and across all care settings?

How are community and service users stakeholders brought to the fore so their needs and perspectives are considered and negotiated in equal partnership with the needs and perspectives of both clinical stakeholders and system manager stakeholders? Please consider The Collective's Statement of Aims to help navigate a path forward. Refer to Attachment 1.

Attachment 1: The Statement of Aims

Purpose of the Statement of Aims

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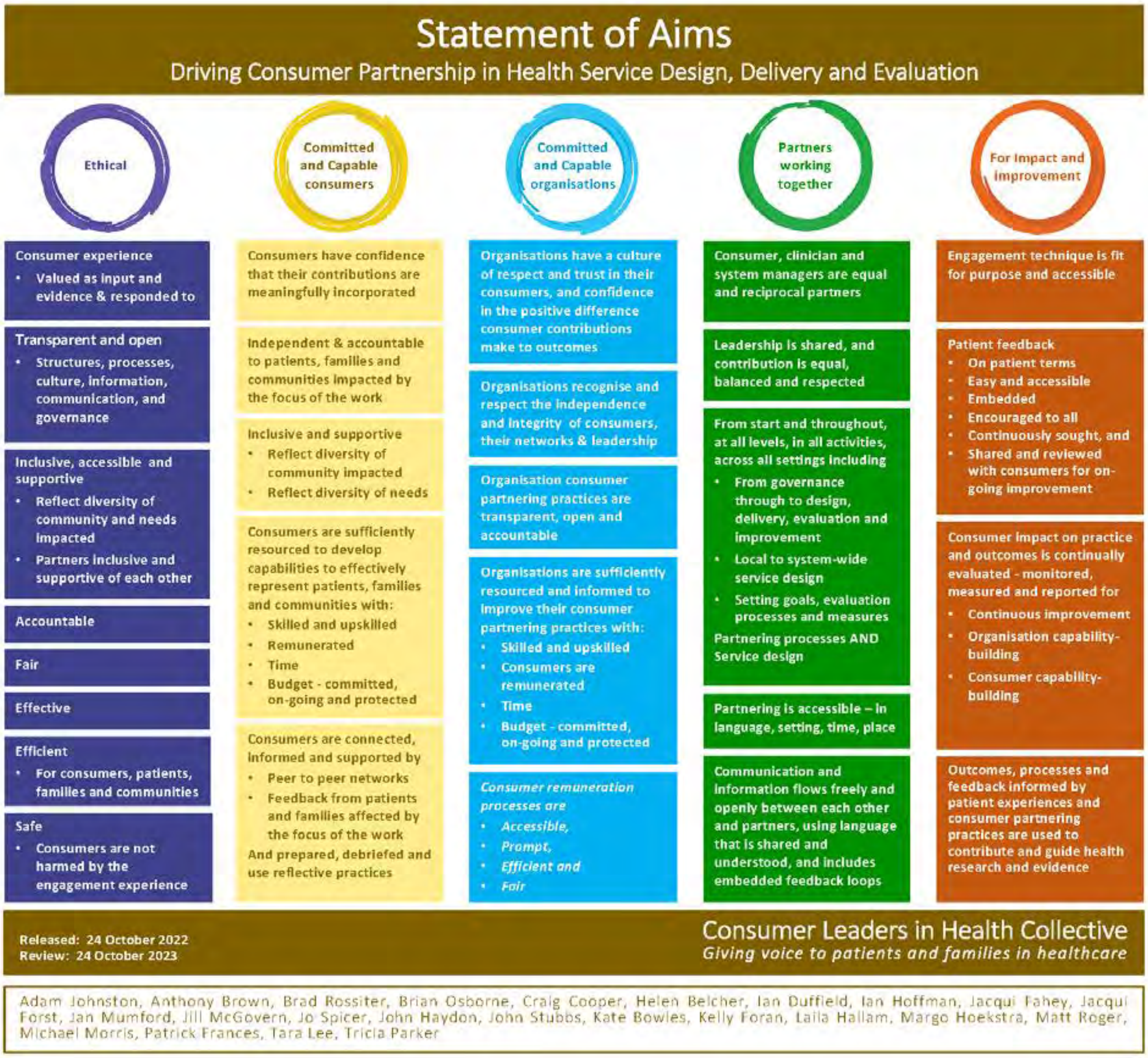

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Effective

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Safe
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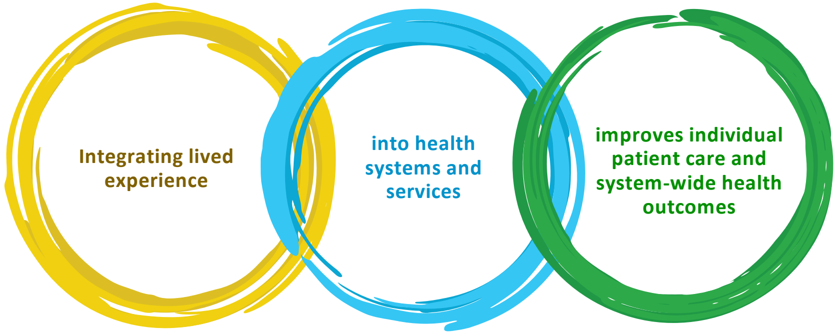

Integrating lived experience

into health systems and services

improves individual patient care and system-wide health outcomes

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