

# Quality Use of Pathology Consumer Consultation Project

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## Executive summary

Pathology is an integral part of the Australian health system with over 30 million tests being carried out each year. Access to pathology services is an essential part of comprehensive health care for Australian consumers. However, **increasing costs, quality of services, and ease of access are presenting increasing problems for consumers**. These are three key issues emerging from a series of consultations on pathology services conducted by the Consumers Health Forum of Australia (CHF) with health consumers around Australia.

CHF is the national peak body representing the interests of Australian health care consumers. CHF works to achieve safe, quality, timely health care for all Australians, supported by accessible health information and effective systems.

Pathology testing can include the testing of blood, body tissues and bodily fluids, which are then analysed to identify diseases and their causes, assess disease severity and monitor disease progress over time. It can also involve genetic testing. Approximately 40 per cent of pathology testing in Australia is for diagnostic purposes, 40 per cent for monitoring and 20 per cent for preventative purposes.<sup>1</sup> The testing process also includes the provision of reports to assist in the diagnosis and management of disease.

In 1999-2000 the Federal Government spent \$1.09 billion on pathology services. This rose to \$1.5 billion in 2007. In 2008, GPs in Australia ordered nearly 18 million more pathology tests than they did in 2000.<sup>2</sup> An estimated further \$1 billion per annum is spent on pathology testing for patients in the public sector to support both admitted and outpatient care. This funding is provided under the National Healthcare Agreement, which is a joint Commonwealth/State funding arrangement in each State/Territory jurisdiction. Pathology plays an integral part in the Australian health system.

In September 2009, CHF was funded by the Commonwealth Department of Health and Ageing (the Department) to undertake the *Pathology Consumer Consultation Project* (the Project). Consumer input, particularly in the context of current reviews of pathology services, is essential. It allows those who pay for, and use, health services to have a role in determining the future of pathology services. The Project aimed to establish an evidence base through consultation with consumers to identify consumer issues, including gaps and opportunities, and facilitators and barriers, to the quality use of pathology (QUP) in Australia.

From a series of eight workshops carried out across Australia in late 2009 and a national workshop in Melbourne in March 2010, as well as through continued input from consumers, CHF gained a wide range of consumer views about, pathology as well as suggested strategies to improve consumers' pathology experiences.

As part of the Project, CHF also developed a literature scoping study of existing academic research related to the quality use of pathology.

From consultations with consumers and written comments on earlier draft reports, a number of issues and concerns were raised, from which a series of recommendations emerged.

Under the broad heading 'Quality Use of Pathology' issues discussed in these consultations included:

- safety and quality of service
- equity of access, including availability and affordability
- adequate availability of an appropriate workforce
- communication between consumer, referrer and provider
- privacy
- point of care testing (PoCT)
- direct access testing (DAT)
- rural/remote issues that relate to pathology
- ehealth and access to pathology results
- genetic testing.

From consultations on these topics CHF has recommended the following strategies:

- the development and implementation of tools to prompt health practitioners to provide better quality information for those undergoing or considering pathology testing
- the development and provision of generic QUP information to consumers
- the development of resources to enhance self management skills and capabilities for consumers
- prompt access to results for consumers and prompt explanation of their meaning followed by written information on those results and subsequent recommendations
- introduction of a Medicare Item Number for a 'Pathology Results' consultation with a GP or other requesting practitioner
- investigation of more widespread implementation of PoCT
- workforce initiatives to deal with shortage of expertise
- increased funding to aid the expansion of mobile collection services to more rural and remote communities
- improved availability of telemedicine services, particularly for the explanation of results
- a greater emphasis on informed financial consent for pathology services
- ongoing consumer consultation and input into any changes to current pathology funding arrangements
- creation of stronger links with other accreditation processes
- implementation of a transparent complaints process to encourage and review consumer complaints in relation to pathology testing
- credentialing of the people who collect samples at collections centres
- continued consumer education about the role of eHealth in improving privacy by enabling secure electronic transmission of information, and the benefits to consumers in improving communication, efficiency, safety and quality.

## Introduction

In September 2009, CHF was invited to inform the Australian Government about consumers' experiences with, and views on, the quality and safe use of pathology. Funded by the Department of Health and Ageing (The Department), the CHF *Pathology Consumer Consultation Project* aimed to consult with consumers in order to identify consumer concerns, including barriers, gaps and opportunities related to the quality use of pathology in Australia.

A series of eight jurisdictional workshops were carried out across Australia in late 2009. Through the workshops, CHF gained input from consumers about their experiences with pathology testing and suggestions for strategies to improve consumers' pathology experiences.

A National Workshop was held in Melbourne in March 2010. This workshop, with a focus on possible solutions, brought together consumers and pathology stakeholders to discuss issues raised in the jurisdictional consumer workshops and responses to CHF's *Consumer Information and Discussion Paper*. As part of the Project, a scoping study of existing academic research related to quality use of pathology was developed. This was provided to the Department as part of CHF's second progress report.

## Key consumer issues

### Safety and quality of service

Most pathology laboratories meet rigorous accreditation standards that are designed to ensure the quality of pathology services received by consumers. All laboratories that participate in Medicare funding arrangements must be accredited, and this has been the case since 1986. There is consumer participation in the ongoing process of development and review of these standards. However, safety and quality of pathology services was an area of consistent concern for consumers. Many consumers provided examples of negative experiences with pathology directly related to poor safety and quality of service.

Throughout consultation, CHF members argued for all pathology tests within Australia to be the 'right test at the right time on the right patient for the right clinical conditions.' Consumers continually highlighted that this was not always occurring. It is imperative from consumers' perspectives that the tests they receive benefit them, rather than cause harm. Tests must be accurate and appropriate for the patient and for the situation, and there must be comprehensive explanation of results as well as prompt follow up on results when this is required.

A possible concern for some consumers is that, in recent times, there has been a huge increase in the volume of pathology testing. This may be due to factors such as the ageing of the population and increasing incidence of major disease (such as heart disease and diabetes, which both require regular pathology testing for effective management). It may also indicate expensive and unnecessary testing being performed on 'worried well' patients. This increase in testing could lead to an increase in false positive results. (A false-positive result is a finding which indicates the presence of a disease or condition which actually is not present. A false-negative result is a finding which indicates that a disease or condition is not present, when it actually is present.) There are also claims that testing for a disease or condition before symptoms appear could harm patients.<sup>3</sup>

In 2006-08, at least one pathology order was requested in 18.7% of all GP encounters.<sup>4</sup> Some of these tests are performed on patients with no obvious symptoms, and, where abnormal results are obtained, this may be due to disease but may also be of no significance (despite falling outside the 'normal' range). This second circumstance can lead to adverse outcomes for patients.

Some consumers also expressed concerns over their practitioners' motivation for requesting pathology testing. Some consumers indicated they had felt pressured by practitioners to undergo testing which would be used for research purposes or because the practitioner received other benefits for requesting testing. There were feelings of concern that practitioners might receive 'kick backs' from pathology providers for referring consumers for testing. The changes to the laws relating to anti-inducement in pathology that came into effect on 1 March 2008 aim to prevent this.

Several consumers reported their frustration when they were referred for testing (for example by specialists or hospitals) when they already had up-to-date results for the same tests (for example from their GP or public hospital). Consumers were concerned that this was unnecessary testing and again were not sure of the requester's motivation.

#### **Case study**

A consumer attending a public hospital provided results from recent tests conducted by a private provider on admission. Staff at the public hospital refused to look at the results. Subsequently the consumer spent five days in hospital undergoing treatment that was later proved to be unnecessary, and would have been avoided if hospital staff had reviewed her results.

Errors in testing were a major concern for consumers. An article looking at health experiences in seven countries, Australia, Canada, Germany, The Netherlands, New Zealand, the United Kingdom and the United States, was reviewed as part of the literature scoping study.<sup>5</sup> The study found that one out of four American adults reported that diagnostic results were not available at the time of care or that a duplication of testing had occurred. Dutch consumers were the least likely to find this. Twelve to 20 per cent of adults (with Australian and American consumers being the highest) had reported at least one diagnostic error within two years. The United States had the highest rate of lab test error, while Germany had the lowest.

The treatment of consumers following inaccurate or false positive or negative results was an issue that was vigorously discussed in consultations. Some consumers indicated they had received treatment for years for a condition that later turned out to be misdiagnosed based on inaccurate test results. Related to this was the experience of not being informed of results, particularly when this resulted in serious implications for consumers or others. Consumers want to be told in a timely manner if they have results that indicate a problem or require follow up. There were several examples cited of consumers not being informed of serious results at all.

#### **Case study**

A consumer told the story of a friend who went for a range of routine sexually transmitted disease tests. She was later told over the telephone that she was HIV positive. The consumer had the test again and it was revealed her previous result had been a false positive. This case study also raises issues about how potentially life changing pathology results are communicated.

Some consumers indicated that they also have concerns about the safety and quality of pathology equipment and the standards in place. Some consumers raised the issue of the differences between results from different pathology laboratories. They found this created confusion for both themselves and their practitioners when using different laboratories, and were concerned this could result in incorrect medical decisions and diagnoses being made.

#### **Case study**

A consumer with experience of prostate cancer highlighted the differences between laboratories which could affect safety. When carrying out PSA analyses, each laboratory tests for different proteins and, consequently, obtains different results. The consumer, located in Queensland, has two laboratories he can attend. Each has purchased different systems to carry out their analyses. He was having regular PSA tests to monitor a steadily rising PSA level. The figure had reached the low 20s and his specialist had told him that once it reached 25 he should go onto androgen deprivation (hormone) therapy to shrink and slow the tumour growth. His PSA tests were being carried out by Lab A. A change at his local medical practice meant that his next test was conducted by Lab B and the figure was 15. His initial reaction was to think that "all his Christmases had come at once," however, his GP ordered a repeat test from Lab A and the result was in the low 20s again. This reduced choice for the consumer by forcing him to stay with Lab A.

### **Equity of access**

Another concern for consumers in relation to the quality use of pathology highlighted regularly throughout consultation was equity of access for all Australians. It was a particular concern for those living in rural, remote

or regional areas, consumers with disabilities, culturally and linguistically diverse (CALD) consumers, older consumers and consumers from low socioeconomic backgrounds.

Equity of access can refer to the availability of facilities, services and tests, affordability of services and availability of the workforce to ensure availability and affordability. Consumers' concerns about equity of access related to a range of areas such as out of pocket costs, access to a wide variety of pathology tests, choice of different laboratories or collection facilities and physical access to tests and collection facilities.

### **Availability for all consumers**

The availability of pathology tests is a significant issue for Australians, particularly for individuals living in regional, rural or remote areas where a full range of tests may not be available. Another concern related to availability is that not all tests are offered in all states or territories, in all towns or in all laboratories. This is particularly true for some genetic or other specialised forms of testing.

Access to a range of providers is another, related issue. Currently, Medicare benefits are only payable to the provider nominated by the requester. However, in the 2009/2010 Federal Budget, changes were announced which would enable patients to choose any provider for their tests. This would mean that individuals would have more choice around which provider undertakes their testing. This proposed change in legislation has been strongly supported by consumers advocating for choice in their health care. The changes are expected to take effect on 1 July 2010.

Consumers want collection centres to be accessible and sensitive to all consumers and their needs. This would include, for example, providing a safe and accessible environment for consumers with a disability, and providing information in languages other than English for CALD consumers.

#### **Case study**

A consumer confined to a wheelchair and with very little movement was told by a collection centre staff member to 'jump up' onto the bed so a sample could be taken. Obviously this caused stress for the consumer. The inability of the staff member to collect a sample from the consumer in his wheelchair also prevented the consumer from accessing the tests he required.

Consumers informed CHF that they are often only offered the choice of one collection point or laboratory for testing, with speculation that this is because their practitioner has a relationship with that provider or because their practitioner prefers the methods of a particular pathology laboratory. Consumers often expressed surprise when told during the workshops that they would soon have a choice of which pathology laboratory to use. Some consumers said they would not feel comfortable questioning their practitioner's referral and would go where they were referred, even if it was inconvenient or they did not like something about the collection centre.

### **Affordability**

An important concern identified by consumers during initial consultations relates to the cost and affordability of tests. This has been highlighted as a particular concern in recent times due to concerns about access to bulk billing. Out-of-pocket costs were identified as being an important factor in whether or not a patient will undergo recommended pathology testing. Some tests (for example genetic testing) might be expensive, and some forms of tests are not subsidised by Medicare (for example, the Thinprep pap smear).

In the 2009-10 Budget, the Australian Government announced new bulk billing initiatives that came into effect on 1 November 2009. The new initiative put the bulk billing incentive for pathology services between \$1.60 and \$4.00 an episode depending on the type of test and location they are collected from. Over four years average Medicare benefits per pathology episode (collection and test fees) will decrease from \$69.17 to \$66.26, creating a difference of \$2.91 per pathology episode. In response to changes in the Budget, several pathology companies wrote to medical practitioners encouraging them to restrict bulk billing to consumers who practitioners 'believed' to be financially disadvantaged.<sup>6</sup> Overall, consumers reported a lack of bulk billing pathology providers, which was of great concern to some of them.

Cost is a factor that can have serious implications for consumers' access to pathology testing. An American study has investigated how often medical practitioners consider patient out of pocket costs before ordering

diagnostic tests.<sup>7</sup> The study revealed that only 40.02 per cent of medical practitioners in the study considered patient out of pocket costs when requesting testing.

A study by Doggett<sup>8</sup> confirms cost is a major concern for consumers when considering pathology testing and other medical procedures. According to Doggett, 17 per cent of consumers had skipped a medical treatment or test recommended by a practitioner due to the cost. This can have serious implications for the consumer. This shows the importance of ensuring adequate access to bulk billing collection centres.

Some consumers identified that they “cost shift” if testing is too expensive. Instead of going to a collection centre (where they will not be bulk billed), they present at a public hospital emergency department for testing. This takes up hospital time and money and makes long term continuity of care more difficult.

#### **Case study**

Some consumers identified that, with particular tests, if they chose to undergo the test they would have to forgo other essential expenses because of the cost. In most cases this means they do not have the test.

#### **Adequate and appropriate workforce available**

According to recent reports<sup>9</sup>, there is currently a shortage of workers in the pathology field, from specialists (pathologists) to medical scientists, technical staff and the people who collect and administer the specimens. This could in turn affect availability and affordability of, and access to, pathology testing. A workforce shortage to carry out pathology testing could have serious ramifications for consumers and their ability to access tests. Measures which were announced in the 2009-10 budget aim to combat workforce shortages by providing \$17 million towards training and support for pathologists. Options are also being explored to find better ways to recruit and retain scientific staff in pathology laboratories.

Some consumers believe they are already seeing the effect of pathology workforce shortages, with longer waiting times and fewer staff at collection points than in the past. During the National Workshop, consumers and stakeholders identified the importance of attracting and retaining qualified staff.

The adequacy of training given to pathology collection centre staff was also a concern. Consumers reported a distinct difference in the skills of private pathology collection centre staff when compared to public pathology collection centre staff.

#### **Case study**

A consumer went to have blood taken for pathology testing. After several failed attempts to draw blood, the collector began using the same needle, which became increasingly blunt with each attempt. After more than 20 attempts the consumer was told to go to a different collection centre and not to return as she was ‘too difficult to take blood from’.

#### **Communication**

One of the biggest issues arising from CHF’s consultations on QUP was poor or a general lack of quality communication between the consumer and their referrer. Full disclosure and informed consent were identified as key issues for consumers in relation to pathology testing. This illustrates that consumers have recognised the importance of being fully informed about services and tests requested for them, and seek full disclosure on all options, costs and possible treatments in the present and future. Consumers also identified the importance of communication about their test results. Many consumers indicated they want to be provided with copies of their results with full explanations of what the results mean and how they will affect their ongoing health care. During the National Workshop, consumers and stakeholders discussed the possibility of consumers being provided with a copy of their results with an easy to understand, jargon-free interpretation.

An article by Struell et al<sup>10</sup> confirms that thorough communication between practitioner and consumer is important to consumers. This is particularly true in relation to medical decision making after receiving test results. Forty per cent of consumers in this study indicated that they want more information from their practitioners than they receive.

Informed consent has been identified also by some consumers as particularly important when it comes to decisions being made by alternative decision makers for minors or people with a decreased capacity for decision making. Consumers wish to be provided with as much information as possible in clear, easy to understand language so that they can make well informed, decisions about their health care and treatment based on as much information as possible.

Consumers in CHF's consultations identified that information is not always made available to them around pre- or post-testing requirements or effects (for example, fasting). Some consumers also indicated they would like to know the chances of receiving a false positive or false negative result.

Consumers also indicated that issues around communication can be particularly important for consumers from culturally and linguistically diverse backgrounds. Huang et al<sup>11</sup> investigated the importance of cultural consideration by medical practitioners taking pathology samples and relaying results to consumers from culturally and linguistically diverse backgrounds. This article identified that consumers from some cultural backgrounds prefer family members to be informed of their test results before they are. This could raise privacy issues in the Australian context.

The way in which information about testing procedures is presented and communicated to consumers from culturally and linguistically diverse backgrounds is also important. Chan et al<sup>12</sup> investigated the differences in the way African Americans, Hispanics and Caucasians prefer to have information given to them about pathology testing, in particular regarding prostate screening. The article identified that cultural sensitivity is essential in creating culturally appropriate brochures and literature.

Decision aids, provided to help consumers make decisions about the risks and benefits of undergoing testing, are not readily found for pathology tests. The importance of decision aids is discussed in a study by O'Connor et al.<sup>13</sup> The study argues that decision aids improve consumers' knowledge of options and choices and reduces difficulty with decision making, while increasing the consumer feeling of participation.

The way in which test results are communicated to consumers was an area of much discussion. Consumers expressed a desire to receive significant test results from their doctor rather than a practice nurse, manager or receptionist. Consumers discussed the importance of the way in which results are conveyed as being important as well.

#### **Case study**

A consumer had a pathology test for tuberculosis while in hospital and was discharged before the result came back to the ward. A positive result was reported and attached to the hospital file instead of being communicated to the consumer. Tuberculosis is a notifiable disease. The error was only found when the consumer was admitted to a different hospital and the file was forwarded. This created great concern for the consumer and their family.

## **Privacy**

Throughout consultation, consumers raised concerns around privacy and pathology testing, specifically around how their results are handled. Consumers do not want their test results to be available to everybody, but they do want to have access to their own results.

Consumers recognise the importance of ensuring positive identification of both the patient and the pathology sample. It is essential that the person administering the test or taking the sample ensures correct identification of the patient at the time the sample is taken and then correct labelling of the sample before analysis. Ramifications of an incorrectly identified sample could be catastrophic for the consumer. Unfortunately, there were many examples provided by consumers of samples being attributed to the wrong consumer.

### Case study

A consumer was called by a practice receptionist and was told that his test results had arrived. The consumer replied that he had not had any tests recently. The receptionist disagreed and proceeded to tell him 'his' results. Finally the consumer managed to convince the receptionist the results did not belong to him and it was established that the results actually belonged to a consumer with the same name and a similar medical history and date of birth. This could have had serious implications for both the consumer to whom the results belonged and the consumer who was called.

### Point of care testing

Point of care testing (PoCT) in particular was a topic that prompted vigorous discussion by consumers in all states and territories throughout the nine workshops and via email and online discussion boards.

PoCT is testing performed by a doctor, nurse or another individual near to or at the site of patient care (such as the hospital emergency department, operating theatres, intensive care wards, GP office, workplace or home). PoCT has existed for decades (for example, pregnancy and blood glucose testing or dipstick urinalysis); however, the emergence of new technology, increasing pressure on hospitals and the changing role of consumers is causing an increase in the types of PoCT available and its use.

Some advantages of PoCT that have been highlighted during consumer consultations include:

- PoCT provides easy access to a range of testing. This was seen as particularly positive for consumers with chronic or ongoing conditions that require regular testing (for example, diabetes).
- The quick turnaround time for results was seen as particularly attractive for consumers, even more so for those consumers with chronic or serious illnesses that require frequent pathology testing with a need for prompt results.

Consumers particularly liked the idea of playing a role in their own health care. PoCT was seen as a form of pathology testing that would allow them to take control of their health and empower them by giving them responsibility for and input into their health care. It was seen as a good tool for promoting knowledge of one's own health and health care needs. The Department recently released the Executive Summary of its *Point of Care Testing (PoCT) in General Practice Trial*<sup>14</sup> the study found PoCT had a role in assisting primary carers and in helping consumers to engage in their own health self management.

For consumers in regional and remote areas, PoCT was seen as providing one solution to the problems with accessing pathology testing. Many consumers at the workshops reported having to travel long distances (in some cases travelling more than three hours) to access pathology testing. The ability to quickly and easily access some tests and obtain immediate results was attractive to them.

Some potential disadvantages include:

- Some consumers expressed concern that PoCT will result in increased inappropriate or unnecessary testing (due to less informed initiation of testing), resulting in increased costs for health care delivery.
- Inaccurate or misinterpreted results are also of concern, particularly when a test is completed by the individual without medical supervision. Quality control of PoCT machines was another concern that was raised. Consumers want to be reassured that PoCT devices are properly and accurately calibrated and that there are clear and easy to follow instructions on how to use them so that results are accurate.
- Cost was another area in which consumers raised concerns. Few consumers involved in CHF's consultations had a good understanding of the cost of PoCT, whether individual out of pocket costs or the cost to the health care system. The DoHA report gives a clearer understanding of possible costs of several tests and indicates that PoCT does not appear to be cost effective. However, these results do not take into account other positive health benefits that would emerge as a result of PoCT.

- Currently, PoCT is not funded under the MBS unless the provider and laboratory are covered under national pathology accreditation arrangements. Most of the consumers consulted would welcome any move to list PoCT on the MBS.
- The DoHA trial also concluded that patients, GPs and those operating the devices were more satisfied with PoCT in most areas; however, pathology providers had no change in the level of satisfaction. The study did not find any differences between users in different geographic regions such as rural, remote or urban areas. Overall, the study found PoCT had a role in assisting primary carers and in helping consumers to engage in their own health self management.

### Direct access testing

Direct access testing (DAT) allows the consumer to take control of their own health care by ordering pathology tests directly from providers without a request from their treating doctor. DAT has reportedly become more popular in recent times due to the rise in available technology and consumers' increasing awareness about their own health and wellbeing. DAT usually refers to when consumers collect their own test sample and send it through the mail to be analysed. Examples of DAT discussed throughout consultation included the recent Australian bowel screening program, genetic testing via the internet and chlamydia tests via mail.

Some advantages of DAT, outlined by consumer consultation included:

- Empowerment of the consumer by allowing them to take responsibility of their health and to monitor their own health
- The possibility of reduced cost to the consumer by eliminating the need to pay for referral
- Assistance in more efficiently monitoring and managing chronic conditions.

Some disadvantages of DAT include:

- Consumers may not be able to interpret results accurately. This can result in a lack of action or incorrect decisions being made about one's health care. It may also result in the lost opportunity for connecting to appropriate support or specialists.
- An increase in unnecessary tests might occur, simply because they are readily available.
- There may be issues with quality control and assurance of good quality clinical standards. Some issues that were highlighted during consumer consultations are that the way in which an individual collects their own sample may contaminate or change the sample, and if the sample is posted or sent away, the sample does not survive the transportation because the relevant transport requirements were not known or followed.

#### Case studies

A consumer has seen a direct access test for sale in a pharmacy, which claimed to test for gluten intolerance. After taking a finger prick blood sample, the test claims it will give a positive or negative result in less than five minutes. There is no blood test for gluten intolerance and the test in fact is for serology for coeliac disease. However, the blood test in itself provides an incomplete diagnosis for coeliac disease, as a small bowel biopsy is required to confirm the diagnosis. This test could be misleading for consumers and cause them to self diagnose and make health decisions that are unwarranted or unhealthy.

Consumers attending a recent car festival were offered DAT for chlamydia. This offered consumers (particularly those who might not be inclined to seek out services) the opportunity to access test services which they might not ordinarily have sought.

### Rural/remote issues

Access and availability of testing facilities for consumers who live in rural and remote areas of Australia is a key issue that repeatedly emerged throughout the Project.

For high end users of pathology, living in a remote or rural region can present unique challenges both in terms of reaching a facility to have their tests done and then the time which it may take for their tests to be analysed and for them to eventually receive their results.

A lack of choice is a significant issue for consumers living in regional/remote areas. They are often forced to go long distances or to a single provider simply because there is no other option. Further to this, consumers have identified the restricted availability of some testing as another concern. Not all tests are available at their nearest collection point, which is a particular concern when testing for complicated or rare conditions.

The use of eHealth and telemedicine was proposed as possible solutions to the unique challenges faced by consumers living in rural and remote areas who need to access pathology services. PoCT is another tool consumers would like to see used more by consumers in rural and remote areas. However, a study by Shepherd et al<sup>15</sup> identified the need for practitioners in rural and remote areas to have more access to training and support when using PoCT.

#### Case studies

Consumers in some areas of Australia have to travel several hours to have pathology samples taken. From here, the sample may need to be sent to another town and the delay in results can be up to a month. The storage and transportation of supplies and the possible deterioration of the sample over time was seen as another concern.

A consumer living in Port Hedland WA has to travel almost three hours to Karratha WA to have pathology testing done, even when unwell.

### eHealth and access to pathology results

In recent times, there has been significant discussion around eHealth, including how it may help or harm consumers in relation to pathology results. Throughout consultation, eHealth was consistently brought up as a possible solution for pathology issues.

Smart requesting and smart reporting are two areas of eHealth related to pathology that have been emphasised as being a possible positive development for consumers. The ability to send requests directly from doctor to laboratories could save consumers' time, as well as eliminating confusion in laboratories from illegible writing on request forms. Electronic reporting by pathology laboratories could enable results to be sent to a variety of different stakeholders (for example, the consumer, the GP and the specialist). This can include images.

A series of papers by researchers at the University of Sydney have investigated the benefits of computerised pathology test ordering. These studies established that electronic ordered testing reduced test turn-around times in hospitals<sup>16</sup> and also reduced the rate of test results being missed when compared to paper ordered tests.<sup>17</sup> Another study investigated whether or not electronic test requesting resulted in improved test result follow up.<sup>18</sup> It concluded that it did in the majority of cases, but not 100 per cent of the time. As a result, further study is required.

Another possible benefit of eHealth and electronic health records is that health professionals could see if a test has already been performed and assess whether it needs to be repeated, potentially requiring duplication of testing.

Although privacy and eHealth was discussed during each workshop, consumers were in general accepting and enthusiastic of the possibility of using eHealth for pathology. Most consumers thought the privacy risks to be minimal and were in support of expanded eHealth systems.

#### Case study

A consumer was told by a health practitioner that she was only able to attend a certain pathology laboratory (which happened to be some distance away from her home) because that pathology laboratory was able to send the results electronically to the practitioner. The consumer would have preferred to attend another pathology laboratory but this laboratory's systems were not compatible. This resulted in strain (physical and financial) on the consumer, who was required to travel to access testing.

## Genetic testing

Genetic testing is an area of recent growth in pathology services due to advances in technology and increased consumer awareness. It was a topic of great interest to consumers, one which they identified wanting to learn more about.

A concern some consumers identified was that the current availability of genetic testing is inconsistent throughout Australia. In addition, the lack of knowledge among both consumers and medical practitioners about this relatively new area of pathology service and lack of availability in all locations may prevent some people from accessing some genetic tests or having a test requested for them. However, since these consultations CHF notes that the National Health and Medical Research Council (NHMRC) have released a resource '*Medical Genetic Testing: Information for Health Professionals*' which will provide practitioners with comprehensive, up to date information on what genetic tests are available. This aims to assist patients considering genetic testing, as well as helping the practitioner to order the appropriate test, interpret the results accurately and provide follow up care to the patient and family.

A genetic test that indicates an increased risk of developing a disease due to a mutation in a gene or genes usually requires expert interpretation. This result does not provide information such as how quickly the disease will progress, or how it will need to be managed. A further concern for consumers around genetic testing is the serious ramifications that may result from the test results, which may include, for example, eligibility for insurance. It is essential that quality genetic counselling and discussion of the results and what they mean is provided to the consumer. This is obviously a particular issue for DAT genetic testing and for those in rural or regional areas where the resources or workforce may be insufficient to provide this.

Consumers often feared discrimination might occur after undergoing testing. A study by Lapham et al<sup>19</sup> investigated these consumer fears. The study was undertaken by 332 consumers who were members of a genetic support group. The study showed that some consumers (nine per cent of the sample) refused to undergo genetic testing for fear of discrimination. Consumers identified they were concerned that genetic testing could result in refusal of life insurance, health insurance<sup>20</sup> or a job. The major finding of the study was that consumers fear the consequences after undergoing testing.

Consumers in all workshops agreed that counselling (including both genetic counselling and emotional support) is essential for quality use of pathology, for those contemplating undergoing genetic testing and throughout the process. Consumers were concerned that genetic testing is currently occurring without follow up support. This is a particular issue if tests are accessed directly from the internet.

Consumers were apprehensive about the cost of genetic testing as those who had experience with it found it was frequently not covered by Medicare, and as a result the cost could be prohibitive.

Some consumers had the experience of asking for genetic testing and being discouraged by their health professional, whereas other consumers felt forced or pressured by practitioners to undergo testing. This divide sparked considerable discussion, with consumers agreeing that it is imperative for health practitioners to listen to consumers and allow them to play a role in decisions about their own health care.

### Case studies

A consumer reported that her 18 year old daughter had been offered a 'routine' genetic test by researchers targeting school-aged males and females. Little information on the test and possible outcomes was provided to the family prior to the test. The results identified that the daughter had a genetic condition and this was conveyed to her over the telephone. The shock of receiving these unclear and unexplained results over the telephone caused the daughter to faint. Her mother was told she could not have further information as her daughter was 18 and had reached the age of consent.

A consumer told the story of undergoing paternity testing for her son. The results were sent in the mail to herself and the father of the child, who was not her partner. This had serious implications for the consumer and her family. No follow up counselling, support or mediation was offered.

## Discussions and recommendations

### Health literacy and pre-test communications

Two key issues that were identified by consumers were the importance of improving consumer health literacy, and the need for more and better information to be communicated to consumers prior to testing.

Consumers identified that there is a great need to promote health literacy among consumers, particularly around the quality use of pathology. Several key areas of information that consumers consider need to be addressed, before they are referred for testing are:

- Why they are being sent for the test?
- What the test will show?
- Chances of getting incorrect results (false positives/negatives)?
- Possibilities and other options or outcomes if the consumer prefers not to have the test.
- The consumer's right to accept/refuse the test
- Information about cost/out of pocket expenses
- What will happen once the test results are available? (e.g. Will doctor call? When?)
- What the consumer needs to do in preparation for the test (e.g. fasting)
- Who might have access to the test result (e.g. insurers) and what are the potential consequences for consumers?

Consumers were also concerned about how to best ensure that all consumers receive this information, including those from CALD backgrounds, people with disabilities, and those with low literacy, given the demands on the time of GPs and specialists. It was also seen as essential that the information provided is correct, clear, up to date and comprehensive and that consumers have the opportunity to seek additional clarifying information.

### Recommendations

There was clear agreement that health literacy of consumers around QUP could be vastly improved through a combination of measures.

#### CHF recommends:

- Development and implementation of tools to prompt health practitioners:  
GPs and other practitioners ordering tests should be prompted at the point a test is ordered to discuss key information (as outlined above) with their patients, and to provide printed or other information and/or appropriate additional resources, such as websites, to their patients to supplement the information provided. A useful website with this information is <http://www.labtestsonline.org.au>.

- Development and provision of generic QUP information:

Consumers recognised that it is not always practical for requesting practitioners to provide all information that consumers need at the time a test is ordered. For this reason, much more information needs to be available to consumers in written and other forms. It was agreed that consumers should be provided with generic information on tests (including in the form of pamphlets, online information, interactive programs, DVDs etc) to be take with them after their appointment with the requesting practitioner or from the pathology collection centre.

All information provided to patients should be evidence-based and easily accessible, and should at a minimum include information on the reasons for a test, the science behind the test and the process and

timing of the test. From the beginning, information which is developed for this purpose must be designed to meet the needs of all consumers, including those with low literacy, those with a disability and those for whom English is a second language.

- Development of resources to enhance self management skills and capabilities:

Resources need to be devoted to empowering patients to be proactive consumers in the area of pathology by providing them with tools and information.

**CHF recommends:**

- providing consumers with a list of common questions that they can ask their requesting practitioner or pathology provider in relation to tests that are ordered for them
- improving and then widely promoting to consumers the online resource [www.labtestsonline.org.au](http://www.labtestsonline.org.au)
- funding key consumer organisations to undertake peer education on QUP or to include QUP as part of training and development in chronic conditions self management.

**Post-test information**

Consumers identified the need for post test information to be provided to consumers in a sensitive and timely manner. Consumers argued that this does not currently occur consistently. Consumers should receive information including their test results, an explanation of what the results mean, and information on how the results will affect their ongoing health care.

Workshop participants agreed that there is no single best way for consumers to receive test results; what is needed will vary depending on the consumer and the severity of the condition around which test results will be provided. It was agreed that the referring doctor has responsibility to ensure that post-test information is relayed in a timely manner and preferably in a private conversation between a health care practitioner and the consumer, not communicated by a receptionist in a public space.

**CHF recommends:**

- Consumers should be able to access their test results

Consumers who wish to access their own test results should be able to do so, either by having a copy of the pathology report sent to them in the mail or by being able to access information electronically. Ideally results sent to the consumer should be presented in a 'user friendly' format, using simplified language and containing phone numbers and links to support organisations.

- Consumers should have prompt access to their test results

Consumers should receive test results within a matter of days after they have been completed (not weeks). If the time taken for the results to be delivered is likely to be longer, consumers should be kept informed about likely timeframes.

- Consumers should always be made aware of their test results

Consumers should always be informed their test results, whether positive or negative. The requesting practitioner should be responsible for delivering this information in an appropriate manner. Consumers agreed in general, that they want to hear significant test results from their referring doctor as opposed to practice staff.

- A Medicare Item Number should be introduced for a 'Pathology Results' consultation with a GP

Consumers called for provisions under Medicare for a GP appointment to discuss pathology test results. This consultation should be shorter than a standard consultation and should attract a lower payment. This would be valuable for situations in which either the consumer and/or the health care provider wants to discuss test results face to face.

- Consumers should be provided with written information on their test results

Consumers want to routinely receive follow up information in a written form (e.g. a pamphlet) or by reference to a reputable website or health consumer organisation, so they have the opportunity to revisit what has been explained to them by the practitioner at a later date.

### **Rural and remote issues**

A priority for consumers was the lack of access to pathology services for certain groups of consumers, particularly those living in rural and remote communities. People in some communities not only have to travel great distances to have a sample collected, but they may also need to travel to obtain their test result. This is costly, difficult and time consuming for consumers, and in some cases presents a significant barrier to people receiving the services they need.

### **Possible solutions and recommendations**

Consumers consulted argued for changes to Medicare to support strategies that improve access for people in rural and remote communities. A number of specific strategies were identified.

#### **CHF recommends:**

- Investigation of more widespread implementation of PoCT
 

PoCT has the potential to remove or reduce some of the issues for rural and remote pathology consumers. Workshop participants called for more widespread development of PoCT, with an emphasis on training of people in the collection of samples and on linking collectors to appropriate medical supervision.
- Workforce initiatives around pathology
 

Consumers suggested a range of workforce initiatives to improve rural and remote access to pathology testing and requesting. Increased training of general practice staff (including nurses) to collect pathology samples and to discuss test results with patients was seen as being potentially beneficial.
- Increased funding to aid the expansion of mobile collection services to more rural and remote communities
- Improved availability of telemedicine services, particularly in ensuring consumers' results are adequately explained.

It was also suggested that partnerships with the corporate sector might improve access to testing in rural and remote communities. Here consumers described the fact that large companies operating in remote locations, such as mining companies, provide good health facilities to their staff, and might be encouraged to expand these services to other members of the community, if appropriate models for cost reimbursement are identified.

### **Affordability and costs**

Cost of pathology services represents a significant access barrier for many Australians. Consumers identified the importance of easy access to pathology providers who offer bulk billing for pathology services. High out of pocket costs as a result of decreasing access to bulk billing have been identified as a disincentive for consumers to undergo necessary testing. Participants noted that costs issues present particular barriers for people in rural and remote parts of Australia, who must not only pay for the pathology tests, but also for expenses related to travelling long distances for tests and results. High out of pocket costs for testing and an inability to access bulk billing can be especially challenging for consumers with chronic conditions with multiple competing health costs.

The cost differences for consumers receiving pathology services as part of an in-patient stay in a public hospital versus those in a private hospital or receiving services as an outpatient were described as inequitable, and consumers considered that these discrepancies need to be addressed.

### Possible solutions and recommendations

Participants identified the need for much more work to be done to understand the impact of cost on quality use of pathology so that strategies to address this can be identified appropriately.

#### CHF recommends:

- A greater emphasis on informed financial consent for pathology services.

This is a particular issue in light of the increase in private billing and out of pocket costs for pathology services. Consumers should be made aware of what their tests will cost, so that they can seek a bulkbilling provider if necessary and available.

- Ongoing consumer consultation and input into any changes to current pathology funding arrangements

Some CHF members indicated that they were aware of the current Pathology Funding Review being undertaken by the Department of Health and Ageing. There was concern about how changes to current funding arrangements might affect consumer access to affordable testing.<sup>21</sup>

### Accreditation of the pathology process

There was considerable concern about pathology accreditation and an argument for the needs of consumers in this area to be addressed as a matter of priority. The main issue identified is that the accreditation process is limited only to what happens in pathology laboratories. It was agreed that pathologists have 'put their own house in order', but that problems exist at the interface between the doctor, the pathologist and the consumer which fall outside accreditation. Problems were reported, for example, in the ordering of tests, the collection of samples at collection centres and the communication of results. The current accreditation system does not provide any mechanism for consumers to report negative experiences, nor does it monitor systemic problems such as unnecessary testing or unhealthy connections between referring practitioners and pathology practices.

Further, consumers identified that there is limited awareness and understanding of the current pathology accreditation system among consumers, leaving people unaware of how standards are set and monitored. Thus there was a call not only for accreditation to extend to the entire pathology process, but also for greater transparency in the accreditation arrangements.

### Possible solutions and recommendations

Consumers suggested that a more complete system of quality control for the entire pathology process should be explored and implemented.

#### CHF recommends:

- Creating stronger links with other accreditation processes

It is essential to ensure that the interface issues mentioned above are subject to quality improvement through links with other accreditation processes such as the accreditation of GPs through the Royal Australasian College of General Practitioners.

- Implementation of a transparent complaints process to encourage and review consumer complaints in relation to pathology testing
- Credentialing of the people who collect samples at collection centres

This would be an important step to ensure that there is increased transparency and accountability about the collection practices. Development of mechanisms to ensure adherence to proper procedures at collection centres, established with the involvement of consumers so that their experiences of the pathology process can be taken into account, would also play an important role in the credentialing process.

## eHealth and pathology services

There was generally a high level of support for a greater use of technology in transmitting pathology results and aiding communication between requesting practitioners, pathologists and patients. While people want to see speedy progression in this area, they were opposed to the development of electronic applications for pathology reporting and communication in isolation from other developments in eHealth and the development of different systems by different providers. There was concern about interoperability of systems, and about the risk of electronic pathology reporting mechanisms being disconnected from broader, nationally accessible eHealth initiatives.

### Possible solutions and recommendations

There was strong support for legislation to enable implementation of a national eHealth system, which mandates interoperability of software systems between pathology providers and requesting practitioners. Workshop participants also felt strongly that there need to be strong measures (both 'sticks and carrots') put in place immediately to encourage adoption of a uniform eHealth system in pathology, rather than encouraging multiple systems to develop.

### CHF recommends:

- Continued consumer education about the role of eHealth in improving privacy by enabling secure electronic transmission of information, and, the benefits to consumers in improving communication, efficiency, safety and quality.

## Conclusion

Millions of pathology tests are performed each year in Australia. Pathology services are of great importance in preventative health, acute care and management of chronic conditions. Consumers greatly value their access to safe and effective pathology services.

CHF's consultations with consumers resulted in robust discussions and revealed some interesting findings about pathology experiences. Consumers across states and territories had differing experiences and views on what is currently occurring in the pathology field, and also about what they hoped to see happen in the future. However, consumers agreed on the need for quality, safe, accessible and affordable pathology services. Consumers expect providers and practitioners to listen to them and consider their views when making pathology requests, when taking samples and when conveying results. Consumers believe pathology to be an area in which further work needs to be undertaken with consumers to improve on these objectives.

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- 20 In Australia, health insurance is community rated so would not be affected by genetic testing. However, some consumers in CHF's consultations were still concerned with this.
- 21 CHF provided a submission to the Department of Health and Ageing *Review of the Funding Arrangements for Pathology Services Discussion Paper*. It can be found here: <http://www.chf.org.au/pdfs/sub/sub-598-review-pathology-funding-arrangements.pdf>.