Reporting on how Pharmac funds very expensive drugs for rare diseases

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ABSTRACT:

This study explores some of the difficulties surrounding health reporting, illustrated through a journalism article the author has written on New Zealand's drug buying agency, Pharmac, and its approach to funding drugs for rare diseases. The long-form journalism article found that while Pharmac was attempting to allow wider access to medicines for rare diseases, New Zealand patients were still significantly disadvantaged compared to many other countries. The study went on to find there was an increasing need for investigative health reporting, such as this article, but identified many barriers to this. These barriers included, but were not limited to: lack of knowledge particularly for general reporters, translating complex medical jargon to a lay public, the agendas of public relations and non-profit organisations, and the increasing pressure on journalists to do more in less time.

Table of Contents

Introduction

Over the last ten years there has been much criticism of the New Zealand drug buying agency, Pharmac, and its funding of drugs for rare diseases. Pharmac was established in 1993 and has been celebrated for driving down previously soaring pharmaceutical prices in New Zealand (Dew & Davis, 2014). Pharmac does this by entering into negotiations with pharmaceutical companies and "as only one drug within a therapeutic sub-group is usually fully subsidized, pharmaceutical manufacturers compete to place their product on the Schedule to gain market share" (Dew & Davis, 2014, p. 138). Typically drugs for rare diseases are incredibly expensive because of the high cost of research and development compared to the relatively few number of potential patients (Stolk, Willemen, & Leufkens, 2006). Rare diseases are defined by Pharmac in recent consultation documents as being long term conditions affecting one in 50,000 people (Pharmaceutical Management Agency, 2014).

Previously, Pharmac has not funded a number of drugs for rare diseases because they were not deemed cost-effective, although there are a few exceptions such as one patient with Hunter syndrome whose treatment costs around $450,000 per year (Moir, 2011). Cost-effectiveness is one of Pharmac's nine decision-making criteria when deciding whether to fund a drug or not. The basic economic definition of cost-effectiveness is where the benefits of something are equal to or more than set price. To inform the decision on what is cost-effective Pharmac undertakes a Cost Utility Analysis for each proposed medication, which is the assessment of the additional benefits and costs associated with treatment (Pharmaceutical Management Agency, 2012). The benefits of a medicine are estimated using Quality Adjusted Life Years (QALYs) and the costs associated with the treatment take into account the treatment itself and the costs to the health sector as a result of funding the medicine.

Patients with rare diseases and advocacy groups have called Pharmac's decisions unfair because without treatment many patients with rare diseases are likely to die prematurely (Moir, 2011). One of the most vocal groups is the New Zealand Organisation for Rare Diseases who have said Pharmac's decision-making criteria does not take into account moral considerations such as equity, ethics and community values (Forman, 2014). The idea of fairness is very subjective and its definition can vary considerably between groups (Murray & Frenk, 2000). Pharmac's critics often point out that most of these drugs are widely funded by many governments in other OECD countries. Pharmac often justifies its decisions on these kinds of typically very expensive drugs based on the fact it has a fixed budget and they need to provide the best health outcomes for as many people as possible (Dominion Post, 2008). Pharmac has said the asking price for some drugs for rare diseases is too

extreme and those hundreds of thousands of dollars that would be put towards just one person could be put towards a low cost drug for thousands of people.

This study was undertaken because of the complex nature of the issue facing not just New Zealand, but governments worldwide in regards to drugs for rare diseases. Many countries have different approaches to funding drugs for rare diseases with some taking into account cost-effectiveness, while others provide them on the basis that because the conditions are rare and severe they deserve special treatment (Hughes, Tunnage, & Yeo, 2005). Like Pharmac, the Canadian Expert Drug Advisory Committee makes recommendations on which drugs to fund on the basis of a rigorous evaluation which takes into account cost-effectiveness (Clarke, 2006). Clarke argues for new criteria to assess drugs for rare diseases in Canada as, according to him, it is virtually impossible to assess cost-effectiveness of treatments for rare diseases using conventional criteria. He goes on to argue that as drugs for rare disease have been developed the criteria for assessing pharmaceutical funding has not changed and it should have. Other countries which have faced similar issues as New Zealand and Canada are Australia (Lamperd, 2014) and Scotland (Adams, 2013).

The basis of this study was to investigate whether the current Pharmac funding model disadvantaged New Zealand patients with rare diseases. The issue of drugs for rare diseases, and the subsequent long-form journalism article produced in this study, is a good example of some of the biggest issues facing reporters covering health. Through the long-form journalism article I investigate three case studies of drugs for rare diseases which have been denied funding by Pharmac over the last five years. The article looks at the decision-making process behind funding pharmaceuticals in New Zealand. It also looks at the pro and cons of a new contestable fund to be introduced by Pharmac next year, with comparison to overseas examples. The literature review is the subsequent result of the issues encountered while undertaking the investigation and a critical analysis of the literature available. The discussion focuses on my reflections upon the literature from my experience of undertaking this investigation. The conclusion summarises the major findings of the study and gives direction for possible further study in this area.

Long-form journalism: The price-tag of living

The New Zealand government's drug buying agency, Pharmac, has previously been criticised for not funding potentially life-saving drugs for rare diseases because of the price-tags attached to them. Critics have claimed the current funding model unfairly disadvantages these New Zealand patients. But Pharmac argues funding some of these drugs would jeopardise its ability to fund less expensive drugs for thousands of New Zealanders. ***Jessica Roden*** *investigates Pharmac's recently announced new fund for drugs for rare diseases and how effective it's likely to be.*

Andrea Neame has spent her daughter's entire life fighting for her to live.

Initially the goal was just to get her to her first birthday. Then her second. Doctors said she would be lucky to make it to six years old.

Her daughter, Sinead Brown, is now 12 years old and still fighting a severe form of cystic fibrosis.

But Sinead is lucky.

She has a gene mutation that affects just four percent of patients.

That mutation is the only form of cystic fibrosis that has an effective treatment, a newly developed drug called Ivacaftor, known as Kalydeco.

On 5 March Pharmac announced it would not fund the drug for Sinead largely because it was found not to be cost-effective.

This is because Kalydeco comes with a price-tag of $350,000 per year. It is also because Pharmac found Kalydeco would likely only minimally benefit Sinead, a claim disputed by Ms Neame.

Many New Zealanders with rare diseases, like Sinead, are in the same situation.

There is a drug that would likely improve, prolong or save their lives but they cannot afford it and Pharmac refuses to fund it.

Pharmac uses the same criteria across all drugs to assess whether they will be funded, with one of the criteria being cost-effectiveness.

However, critics argue drugs for rare diseases are just not cost-effective. They argue that continuing to measure cost-effectiveness in the case of rare diseases significantly disadvantages these patients.

Pharmac is attempting to widen access to drugs for rare diseases by trialling a $5 million contestable fund starting next year.

Critics say the fund needs to be four or five times larger in order for all patients with rare diseases in New Zealand to have treatment.

However, if the fund is deemed effective Pharmac says it will continue with $5 million added each year.

Though Kalydeco could be funded under the new fund next year, it could also remain unfunded for a number of years.

Ms Neame fears Sinead does not have time to wait (see: **The last hope**).

Sinead's condition has declined rapidly. Over the last three weeks she has lost 5kg making her now 27kg, dangerously below a healthy weight for someone her age.

But with a fixed budget can Pharmac justify spending up to a million dollars on one patient alone per year? That's money that could help thousands of other kiwis afford everyday medicines.

Pharmac's priorities

According to Pharmac director of operations Sarah Fitt, the organisation has to look at the bigger picture. Sometimes that means making "difficult decisions", Ms Fitt says.

"It isn't a bottomless pit and that goes right across the healthcare sector. There's a limit to how much we can actually fund," she says.

Pharmac has been criticised for many decisions over the years, Ms Fitt says.

There have been a number of high-profile cases where Pharmac has denied funding for drugs, largely because they were not cost-effective.

In some instances this has resulted in a shortened life-span for patients or even premature death.

The basic definition of cost-effectiveness is when the benefits of something are equal to or more than the price paid for it.

Pharmac has denied funding of Soliris, the only treatment for two ultra-rare blood disorders, on multiple occasions (see: **The world's most expensive drug**).

It has also denied funding of Myozyme for Pompe disease, leaving some New Zealand patients with no option other than to travel to Australia fortnightly to access a clinical trial (see: **High need but no funding**).

In the case of one patient, Pharmac found her high need did not outweigh the cost-ineffectiveness of Myozyme despite the fact she is likely to die prematurely from the disease.

All these drugs carry a hefty price-tag upwards of $200,000 per year with patients needing to take them for the rest of their lives. The price of some medicines depends on how much of the drug is needed to be effective, which is determined by a patient's weight. It could cost almost $1 million to fund some patients at current prices.

Pharmac's objective is to look at the best health outcomes for all New Zealanders and all diseases, Ms Fitt says.

Drugs for rare disease are typically the most expensive drugs in the world.

Drug companies spend millions of dollars on research and development, but because the drugs can only be used by a small number of people the companies charge an incredibly high price to recoup the costs.

Internationally it is agreed that most drugs for rare diseases are not cost-effective, though some countries do fund them regardless.

Other countries, like New Zealand, evaluate the cost-effectiveness of a drug before it determines whether to fund it or not.

This is just one of nine Pharmac decision making criteria. The criteria are:

1. The health needs of all people in New Zealand
2. The needs of Māori and Pacific peoples
3. The availability and suitability of existing medicines
4. The benefits and risks of the drug
5. Cost-effectiveness
6. Budgetary impact
7. Direct cost to health service users
8. The Government's priorities for funding
9. Any other criteria Pharmac sees fit

There is no weighting between the nine decision making criteria, Ms Fitt says.

Patients who have had funding of drugs denied tend to focus on the price or think Pharmac only considers cost-effectiveness, she says.

“There’s lots of drugs we do approve and we have to look at the bigger picture and we have to make some difficult decisions. It’s not easy at all,” Ms Fitt says.

Drugs for rare diseases are also commonly denied funding because of the budgetary impact criteria.

Pharmac balances how funding one very expensive drug will affect its ability to fund many less expensive drugs. On the other hand there are savings to funding a new drug e.g. less hospitalisations.

Pharmac does fund some drugs for rare diseases such as a patient with Hunter syndrome whose treatment is valued at around $450,000 a year, Ms Fitt says.

There are two ways subsidised drugs are funded in New Zealand, though the same nine criteria apply regardless.

Drugs can be funded under the Pharmaceutical Schedule which means patients only have to pay $5 and doctors are free to prescribe it without having to apply in each instance.

Under the current Pharmac funding model drug companies present their proposal and Pharmac decide whether to put the drug on the Pharmaceutical Schedule.

Currently around 2000 medicines are on the Pharmaceutical Schedule.

When a drug is not on the schedule doctors have to apply for funding for individual patients under the Named Patient Pharmaceutical Assessment (NPPA), which took over from the Exceptional Circumstances scheme in March 2012.

New Zealand is unlike any other country Ms Fitt knows of in the sense that it has a fixed cap spending on pharmaceuticals, she says.

“I think it’s good because we look across the board and we decide what is actually a good investment, you know, for medicines,” Ms Fitt says.

When asked what she would say to some of the patients of rare diseases who have had funding denied she says she hopes they see Pharmac empathises with them.

“We’re not sat here trying to ignore them or be difficult. We really do want to try and progress.”

The Pharmac success story

Pharmac was set up in the context of soaring pharmaceutical prices. It was established in 1993 to manage which drugs were subsidised by the state and get the best price for them.

Drugs that are not subsidised by the government traditionally do not receive a high market share because people do not want to pay for them and doctors are reluctant to prescribe them.

The manufacturers of drugs that serve the same purpose compete against one another.

Whichever drug company gives Pharmac the lowest price will likely have their product placed on the Pharmaceutical Schedule, meaning it is the only fully subsidised drug, and therefore win the most market share. Other companies are effectively shut out of the market.

Before this the Department of Health, which was then replaced by the Ministry of Health, was in charge of pharmaceutical management. This was historically problematic as drugs that were cost-ineffective remained funded, it lacked bargaining power with drug companies and it was seen to be subject to political lobbying.

Since then Pharmac has been celebrated worldwide for lowering the cost of pharmaceuticals and drug expenditure in New Zealand.

Pharmac estimates that between 2000 and 2013 it saved District Health Boards more than $5 billion in pharmaceutical expenditure.

But doctors were initially sceptical, says Chair of the New Zealand Medical Association, Dr Mark Peterson.

Many thought it would give them less variety of medicines to prescribe to patients, Dr Peterson says.

The New Zealand Medical Association represents doctors across the country. Mr Peterson has been a practitioner of medicine for almost 30 years.

“Over the years Pharmac have been able to demonstrate their value,” he says.

Dr Peterson concedes some doctors can be very critical of Pharmac’s approach to funding drugs for rare diseases but says they are in the minority.

“Those people shouldn’t be criticising Pharmac… the criticism, if there is any, should be political,” he says.

“They are given a budget by government which says this is the amount of money we will spend on pharmaceuticals and they have to work within that.”

Mr Peterson agrees that medicines for rare diseases are more difficult to get in New Zealand than overseas.

Some of the medicines being proposed are so expensive and to justify spending so much money, Pharmac needs to be absolutely clear about a medicine’s value and effectiveness, he says.

“Luckily I don’t have to make the decision. It is difficult. There potentially isn’t a right and wrong answer.”

The new fund for rare diseases

In April 2014 Pharmac announced plans for a contestable $5 million fund solely for drugs for rare diseases.

Pharmac defines rare diseases as long term conditions affecting one in 50,000 people.

The fund is still very much in the experimental stages with even Ms Fitt unsure exactly how well it will work.

What is clear is that the fund would still use the nine Pharmac funding criteria, meaning it would only fund drugs that are deemed cost-effective.

The idea is that with up to $5 million available drug companies will compete for an allocation of the money, Ms Fitt says.

Pharmac hopes the competition will encourage companies to submit more cost-effective proposals than they have previously, she says.

The fund will be made up of savings from the NPPA programme in recent years therefore does not require additional government funding, Ms Fitt says.

Currently $8 million is allocated yearly to the NPPA program.

“We’ve decided, based on the sort of feedback we’ve been getting, we can take an allocation of that NPPA money and actually use it to try and address some of the concerns that have been raised,” Ms Fitt says.

Once drugs are funded under the rare diseases fund they will be moved to the Pharmaceutical Schedule. They will continue to be funded under the Pharmaceutical Schedule indefinitely unless the drugs stop showing results.

Once that $5 million fund runs out after the first year, Pharmac intends to assess the effectiveness of the fund. It hopes to continue the fund with a new $5 million added to it each year.

The plan is to have the first patients receiving treatment around the start of next year, Ms Fitt says.

Currently Pharmac is in the process of requesting input from the public and drug companies.

The new fund received a positive response after two Pharmac representatives met with drug companies in Australia last week to encourage proposals, Ms Fitt says.

The general manager of Medicines New Zealand, Kevin Sheehy, says he believes the increased competition for the fund for rare diseases will encourage drug companies to lower their prices for these drugs.

“Yes I think competition may drive down prices a little bit and to a level that it’s affordable in New Zealand because you’ve got the guarantee of future funding,” he says.

Medicines New Zealand lobbies on behalf of around 80 drug companies which market products in New Zealand. Most of the companies it represents it represents has at least one drug targeted towards rare diseases.

From his experience New Zealand patients often have to wait longer than patients overseas to access new drugs, Mr Sheehy says.

“It’s a bit of an unusual situation where [Pharmac] work so hard on cost containment, I think to the detriment of patients sometimes,” Mr Sheehy says.

Critics say that to fund all drugs for rare diseases it would require a pool of funding between $20 and $25 million per year and it needs to be available now.

While $5 million is not a lot at current prices hopefully that increased competition will make some of these drugs more cost-effective, Ms Fitt says.

“The drug price may come back to be significantly different and if it’s something that perhaps wasn’t cost-effective a year ago if we get a good proposal it would become cost-effective,” she says.

The critics

According to one of Pharmac's strongest opponents the contestable drug fund is a step in the right direction but essentially it comes up short.

John Forman has been campaigning for rare diseases for over a decade as the executive director of the New Zealand Organisation for Rare Diseases (NZORD).

The biggest problem he has with Pharmac is that the nine decision making criteria do not take into account moral considerations such as ethics, equity and community values.

"We know that some things are more cost-effective than others but we know that some things are more important than others," he says.

Ethics refers to doing what is right, Mr Forman says.

"In the end if someone collapses in the street the ethical thing is… saving a life and intervening to prevent any future injury."

Equity refers to the fact some people have greater disadvantage than others and the need to address those disadvantages, he says.

Community values is what New Zealanders think is a fair and what should we reasonably expect from our health system, Mr Forman says.

One of the biggest issues with Pharmac taking into account cost-effectiveness for the new fund is that drugs for rare diseases are just not cost-effective, Mr Forman says.

Also, $5 million is not nearly enough, he says.

"It doesn't even need a calculator to figure out it's about one quarter or one fifth of the amount that's needed."

The new fund provides no flexibility for the evidence required which is not fair, Mr Forman says.

The strength of the medical evidence behind some of these drugs has previously played a part in Pharmac's decision to not fund them.

"There will always be poorer evidence for medicines for rare diseases," Mr Forman says.

This is because the medicines are normally very new, less is known about the diseases, drug trials can contain a small number of patients and fewer papers have been published about them, he says.

“There’s an inherent weakness in situations where diseases are rare.”

Mr Forman is also concerned Pharmac may accept a proposal from a drug company because it is the most cost-effective and as a result patients with higher needs could miss out.

“Pharmac is so commercially driven… that there’s a big risk that one drug or one patient group would scoop the pool and get the whole amount,” he says.

There is a need for a special fund for drugs for rare diseases but it needs to be more money and it to be managed elsewhere from Pharmac, Mr Forman says.

The only way all drugs for rare diseases will be funded is through political action, he says.

The issue of drugs for rare diseases became increasingly political last year when the Labour party announced it would implement a $20 million fund for such medicines if it were to win the election in September.

While Mr Forman believes the new contestable fund is a step in the right direction, he says the issues are in the fine print.

“It’s problematic. It’s something. It could be the start but there’s so many fish hooks in it that we don’t have a lot of confidence it will deliver.”

How it’s done overseas

New Zealand is not the only country struggling with how to approach funding of drugs for rare diseases.

The Canadian Drug Expert Committee has also turned down Soliris because it was is cost-effective.

Soliris is the only treatment for two ultra-rare blood disorders, paroxysmal nocturnal hemoglobinuria (PNH) and atypical hemolytic uremic syndrome (aHUS).

The committee has approved the use of Kalydeco but only if the company that supplies it, Vertex, can provide it at a lower price, which is currently under negotiation.

It has also approved the use of Myozyme but only in patients with infantile-onset Pompe disease. Patients with adult-onset Pompe disease, which means it develops later in life, are not funded.

Canada works within a similar framework of New Zealand in that access to subsidised medication is managed by a government agency and cost-effectiveness remains part of its decision making criteria in relation to drugs for rare diseases.

However, both Australia and Scotland have funds allocated to drugs for rare diseases that are specifically not funded because of cost-effectiveness.

In 1998 Australia set up the Life Saving Drugs Program to provide free access for eligible patients to expensive lifesaving drugs for rare diseases.

Currently 10 medicines are funded for the treatment of seven rare diseases. This includes Soliris for PNH and Myozyme for Pompe disease, but like Canada it is only for infantile-onset.

Soliris is generally not funded for the treatment of aHUS, though this month for the first time one patient has been given funding. Kalydeco is currently not funded.

For drugs to be funded it has to be proven to be clinically effective but rejected from the Pharmaceutical Benefits Scheme, the list of subsidised drugs that can be prescribed by doctors, because of cost-effectiveness.

There has to be no alternative treatment available and the cost of the drug has to constitute an unreasonable financial burden on the patient.

In a 2009 review it was found the programme provided a service not covered anywhere else in the health system. The programme is currently under another review.

Scotland has recently established a similar fund after deciding existing cost-effectiveness criteria were not appropriate in the case of rare diseases and end of life care.

Around £21 million, or $NZ41 million, per year has been allocated to the Rare Medicines Drug Fund following its inception in 2013.

Requests to the fund are assessed only after the Scottish Medicines Consortium has refused to fund the drug because it was not cost-effective.

Because drugs are funded on an individual basis it is unclear at this stage which drugs have been funded, though it was thought to be particularly aimed at patients who need Kalydeco.

The gene mutation Kalydeco targets is normally only found in four percent of cystic fibrosis patients, but in Scotland it is prevalent in 11 percent of patients.

Scottish Health Secretary Alex Neil said at the time: “It is only right that Scottish patients with rare conditions have access to innovative medicines which are clinically justified and that they are not disadvantaged due to the very high cost of these treatments.”

Continued disadvantage

Pharmac appears to be making a genuine effort to allow wider access to medicines for rare diseases in New Zealand.

However, the fact Pharmac will continue to measure cost-effectiveness when it comes to the fund for rare diseases means many patients will still be significantly disadvantaged.

The reality is that these drugs are not cost-effective. The companies that market them want to get back the money they spent developing them and therefore charge exorbitant prices to do so.

That is their prerogative. Their role is to be a business and to make money.

But Pharmac is a government entity, not a business.

While the funding model Pharmac uses has been a huge success in the past, in the case for drugs for rare diseases it should be taking a different approach.

Yes, the fund for rare diseases will provide $5 million worth of funding for these drugs next year. This will mitigate the issue, by providing a handful of patients with treatment, but may not solve it.

If a drug company has submitted an application previously that has been rejected by Pharmac because it is not cost-effective, they may not want to submit another application to the new fund.

While the promise of ongoing funding may entice some to submit more cost-effective proposals, drug companies have no obligation to lower their prices for one or two New Zealanders, especially when other countries will pay the asking price.

Even if the fund is given more money in subsequent years, which hopefully it will, it could be too late for some patients.

Only a fund like the ones in Australia and Scotland, which do not take into account cost-effectiveness, will allow all New Zealand patients with rare diseases to have the access to the drugs they need.

These funds are run separately to the pharmaceutical budgets meaning funding drugs for rare diseases does not affect the country's ability to fund drugs for less rare conditions.

In the end it has to be stressed that it is not Pharmac's fault. It has been given a mandate by the government that it has to follow.

If tomorrow the government decided to increase the fund to $25 million, Pharmac would have to follow that too.

To give these patients the same care they would get if they were born in many countries overseas would cost very little compared to the overall Pharmac budget.

In fact, the amount that is being asked for, $25 million, is just 3.2 percent of Pharmac's operating budget, which currently stands at $783 million.

But it shouldn't be about quantifying how much benefit a patient will get from a drug in proportion to how much it costs.

It should be about saying without these drugs these patients will continue to suffer painfully and possibly die prematurely, while knowing it didn't have to be that way.

Case study one: The world's most expensive drug

Not long after Daniel Webby, 33, was diagnosed with a rare blood disorder in 2011, he was admitted to hospital for three weeks with extreme complications.

"There's a high likelihood that my life isn't going to be very long without treatment," Mr Webby says.

He suffers from PNH, which is a bone marrow disorder where some or all of a patients red blood cells are destroyed.

Patients face anaemia, fatigue, severe abdominal cramping, headaches and recurrent infections. They can also suffer blood clots, which are the leading cause of death in PNH patients.

Mr Webby knows there is no cure for the disease, but a treatment which could prolong his life is Eculizumab, commonly known as Soliris.

Forbes magazine once described Soliris as the world's most expensive drug.

On 12 December 2013 Pharmac announced it would not fund Soliris for patients with PNH after almost two years of deliberating.

Mr Webby says he was not surprised when he heard the outcome.

"In the very first meeting the cost was highlighted as a barrier so it would be unlikely to be funded," he says.

During the consultation process 98 percent of submissions supported Pharmac funding of Soliris.

“The primary driver of the outcome of these evaluations is the very high price being sought by Alexion, which is around $670,000 per patient per year,” according to the memorandum of the Pharmac board meeting from November 2013.

In a press release about the decision Pharmac chief executive Steffan Crausaz says it would cost around $10 million to fund 20 patients, which indicates a much lower average price of around $500,000 per patient per year.

These prices do not include rebates which are not released to the public for commercial reasons.

According to the memorandum summary between 12 and 20 New Zealanders with PNH would be eligible for Soliris.

In March 2013 a Pharmac subcommittee found three patients per million population would likely be eligible for Soliris, meaning around 13-14 in New Zealand.

This figure is backed up by a letter written to Alexion on 14 May 2012 by Dr Peter Hillen of the United Kingdom. Dr Hillen has been researching PNH for 24 years and led the initial trials of Soliris.

“In the UK we have been using [Soliris] in PNH on the basis of clear guidelines and have 3 patients on therapy per million population. There is no reason that this would be different in New Zealand,” Dr Hillen wrote.

Soliris was approved by the US Food and Drug Administration (FDA) in 2007 for treatment of PNH patients following two double-blind placebo controlled clinical trials.

In the memorandum Pharmac agrees there is “excellent” evidence Soliris reduces the number of blood transfusions, stabilises red blood cells and reduces haemolysis. It considers there is “good” evidence it reduces rates of blood clots, reduces fatigue and improves quality of life.

There is insufficient, robust evidence to estimate the overall survival benefit of Soliris, according to the Pharmac memorandum.

A major conclusion of a 2011 study from the UK found Soliris “dramatically alters the natural course of PNH, reducing symptoms and disease complications as well as improving survival to a similar level to that of the general population.”

However, minutes from the Pharmac subcommittee meeting in March 2013 found because there is no long term studies it considered it likely someone with PNH would have a shorter life expectancy than the general population, even if they were on Soliris.

The most common side effects of Soliris were headaches, runny nose, colds, sore throat, back pain, and nausea.

Though Pharmac appears to be attempting to address the issue of drugs for rare diseases it needs to happen faster, Mr Webby says.

“Pharmac knows there is a problem here. Effectively it is a form of discrimination… It’s an unintended discrimination,” Mr Webby says.

The mother of four-year-old Jethro Morrow, agrees.

Her son was denied funding by Pharmac on two occasions, Shannon Gantley says.

Jethro was diagnosed with aHUS at eight-months-old. He is the only person in New Zealand known to have the disease, which is associated with anaemia and kidney failure.

The only treatment for aHUS is Soliris, which was approved for use for aHUS patients by the FDA in 2011.

Pharmac denied funding for the drug on the grounds it was not cost-effective and because at that stage Jethro’s aHUS was stable, though it is likely he will go into remission at some point.

“Basically they’re saying your kid’s too expensive to save,” she says.

Case study two: High need but no funding

A Masterton woman suffering from late-onset Pompe disease says it was “gut wrenching” when she first discovered Pharmac would not fund the only treatment available to her.

Allyson Lock, 49, was diagnosed in July 2010 after years of pain that started more than two decades before.

Pompe disease is a muscle weakness that particularly affects core muscles and legs, which can result in severe respiratory failure.

“It was fabulous after so many years of going to doctors to have a name for it,” Ms Lock says.

She soon discovered there was enzyme replacement therapy called alglucosidase alfa, known as Myozyme, which could treat the disease.

Two initial drug trials in 2006 were only conducted on patients with infantile-onset Pompe disease, so children from one month to 3.5 years old.

A later study from the United States in 2010 of patients with late-onset Pompe disease found Myozyme improved walking distance and lung function over 18 months.

However, between five and eight percent of patients who received Myozyme had an allergic reaction or a reaction to the infusion resulting in chest discomfort, vomiting and increased blood pressure among other things.

Ms Lock was devastated on 25 February 2012 when Pharmac denied her funding for the drug.

“I actually thought they would fund it… because without treatment you’re going to die from it,” Ms Lock says.

For Ms Lock, Myozyme come with a price-tag of around $575,000 per year. The price of the drug depends on how much of the drug is needed to be effective which is determined by a patient’s weight.

In the memorandum of the Pharmac board meeting which finalised the decision it says the cost of treatment was very high, especially compared to the health benefit which Pharmac deemed to be only modest.

The document noted that without an effective treatment Ms Lock would likely “become wheelchair bound, ventilator dependent and probably eventually die, most likely as the result of respiratory failure”.

However, it went on to say that “while this patient’s high need gives some justification for funding this treatment ahead of others, on balance we consider this insufficient to outweigh the high cost ineffectiveness of this treatment”.

At that stage the disease was causing an extremely quick decline in her health.

If it were not for a drug trial in Australia which she started in July 2011 she would either be hospitalised indefinitely or dead, Ms Lock says.

Another patient with late-onset Pompe disease appealed to the office of the Ombudsman in 2013.

Freda Evans had two applications for funding of Myozyme denied by Pharmac.

The Ombudsman handles complaints and investigates the conduct of government agencies in New Zealand.

Following an investigation of Pharmac's decisions it was the opinion of the Ombudsman, Dr David McGee, that Pharmac should have considered funding a trial for the patient as was suggested by her doctor in the submission.

While Pharmac director of operations Sarah Fitt could not comment on that particular case as it was before she started at Pharmac, she says generally speaking some trials can be too difficult to conduct.

It is easier with some conditions where you have something you can measure or can easily see an outcome with, she says.

"A trial is a good idea but in practice it is not always feasible."

Case study three: The last hope

The only treatment for an incredibly sick 12-year-old girl in Auckland with cystic fibrosis is Kalydeco.

It is likely Sinead Brown will die in just a few years if she is not treated, mum Andrea Neame says.

Finding out Pharmac would not fund Kalydeco for Sinead earlier in the year was Ms Neame's "rock bottom".

"That was a kick in the guts. That actually took me a week to be able to talk about and come back from," she says.

Around six years ago Ms Neame heard about Kalydeco which is specifically targeted at cystic fibrosis patients like Sinead with the G551D mutation.

At the time it seemed like a ray of hope for Sinead, Ms Neame says.

"The best way to describe it is it's like I've won the lottery and I've got the winning numbers in my hand but they don't want to give me the money," she says.

Kalydeco was approved for use by the FDA in 2012 after a three month review, making it one of the fasted drugs ever to be approved.

A double-blind placebo controlled drug trial of patients 12-years-old and over, found those receiving Kalydeco were 55 percent less likely to have pulmonary exacerbation, worsened lung function, compared to the placebo group.

It also found on average patients receiving Kalydeco gained 2.7kg more than those on the placebo over the 48 week trial period. Some patients receiving Kalydeco did suffer headaches, respiratory tract infections, nasal congestion rashes and dizziness.

Sinead's doctor Pamela Jackson of Dunedin Hospital, where Sinead lived until recently, applied for funding under the NPPA scheme.

In a letter to Dr Jackson informing her of the decision to decline funding, Pharmac medical director Dr John Wyeth attributed it to the cost, but also Sinead's severe condition.

"The evidence shows that they likely benefit that treatment would offer Sinead is minimal. Since the treatment is so expensive (around $350,000 per year), this means that the cost-effectiveness of funding [Soliris] for Sinead would be poor," Dr Wyeth wrote.

Because of Sinead's worsened condition Vertex, who supply to drug, have agreed to give Sinead 28 days on compassionate grounds.

But there is not guarantee Vertex will continue to give Sinead the drug and yet no start date for the treatment, Ms Neame says.

Sinead would have to continue on the drug for the rest of her life for it to be effective.

Ms Neame plans to start awareness campaign hopes that with community support Pharmac will have to eventually fund Kalydeco for Sinead and all other patient in the same situation.

There could be as many as 25 other people in New Zealand who would be eligible for this drug, she says.

Ms Neame is also looking into hiring a lawyer and taking out a treatment injury claim through ACC.

"I believe that I've got a basic human right to access it. My child has a basic human right to access it."

Literature review

Introduction

This literature review discusses the subject areas that are significant to this study. It analyses what has been written previously about Pharmac and the topic of drugs for rare diseases both academically and within the mass media. It outlines some of the issues journalists who cover health face, such as criticism of inaccuracy, speculation as fact, and misleading reporting. It examines difficulties journalists have with reporting on complex scientific information and communicating that back to the lay public. It looks at the need for more investigative health reporting, despite the increasing pressure on journalists to create more content, faster than ever before. In addition, it looks at the fraught relationship between public relations and journalism and the role non-profit organisations can play in finding and reporting on the news. It also explores the difficulties in working on a national story without the ability to interview each subject in person. Finally, it discusses the difficulties journalists face with interviewing vulnerable subjects such as the sick or marginalised in society. To put the review in context, I first discuss the methodology I used in researching the long-form journalism.

Methodology

This section describes how I undertook the long-form journalism article and explains how it relates to the following sections of the literature review. A predominant aspect of the research process included looking into previous literature about Pharmac and previous journalism on drugs for rare diseases. I looked into both for context of controversial issues from the past and present, relevant sources and interviewees, to investigate how Pharmac operates and discover what angles had been covered before in order to find a new and compelling way to tell the story. Therefore, the literature review will discuss these topics, following on from research done in preparation for the long-form journalism.

During my experience undertaking the long-form journalism article I discovered the high value placed on health reporting by the public, medical practitioners and policy makers. For example, a lot of the information I was given from such people was actually sourced from earlier journalism articles. It became apparent the media serves as the main form of information about health issues for many people. Therefore, the importance of health reporting will be discussed in the literature review.

Through my own experience of undertaking the long-form journalism I discovered there are many difficulties with health reporting. The literature review will discuss the three difficulties I struggled

most with: translating medical jargon, general reporters covering health and reporting on health policy. While there is many other difficulties health reporters face, these were the most prevalent during my experience.

Because this study required an in-depth look at a particular topic, through the long-form journalism, it lent itself to becoming an investigative article. I was particularly interested early on about how Pharmac funded drugs for rare diseases, therefore my long-form journalism evolved into an investigative health article. The literature review will look at the role investigative health reporting, such as this article, plays within society.

Because the long-form journalism was a national story I had to conduct most interviews over the phone and occasionally email. This was because of the large number of interviews needed, the limited time and limited funds. While the ideal method, I believe, would have been conducting all interviews in person, it was simply not possible for this study. The literature review therefore discusses the pros and cons of journalists using phone and email and compares this to face-to-face interviewing, which is commonly viewed as the best interviewing method.

Especially when reporting on policy and when conducting an investigation it is usually necessary to interview a person in a position of power to give an article balance. In this instance that involved interviewing a representative from Pharmac. However, in order to set up an interview I was asked to liaise with Pharmac's public relations officer. Therefore, the literature review will discuss the academic writing around both interviewing figures of power and interacting with public relations from the perspective of a journalist.

Lastly, an important aspect of the methodology behind this study which will be analysed in the literature review is interviewing the vulnerable. The topic I chose had a large human interest element to it. In order to discuss the issue in a meaningful and balanced way I interviewed people who were most affected by Pharmac's decisions. Those people were often very sick and discussing very sensitive or personal information. The literature review will discuss the responsibilities of journalists who interview the vulnerable.

Previous literature about Pharmac

There has been much written about Pharmac in academic literature as well as the issues around funding medicines for rare diseases. Pharmac has widely been praised for containing the soaring pharmaceutical prices from the 1980s (Dew & Davis, 2014), placing pharmaceutical decision-making independent of government (Fenton, 2010), and putting a cap on the pharmaceutical budget (Duckett, 2013). According to Cumming, Mays and Daubé (2010) compared to other OECD countries

New Zealand has below average pharmaceutical costs despite the fact public coverage has improved. However, Pharmac has also been widely criticised for being too restrictive of new and/or expensive medicines. A study by Raftery (2008) compared the access to drugs with low cost-effectiveness in Australia, England and New Zealand. He found of the last 10 of these drugs approved for funding in the UK, six were approved in Australia and five in New Zealand. Other literature found similar restrictions in NZ on access to new and/or expensive medicines compared to the US, UK and Australia (Wonder & Milne, 2011; Ragupathy et al, 2012). There has also been extensive writing about the issues surrounding funding medicines for rare diseases. A study by Hughes, Tunnage and Yeo (2005) found that while the European Union regulations promote the development of drugs for rare diseases, some health care systems have to assess cost-effectiveness to contain costs. They argue it results in unequal access to drugs for rare diseases across Europe (p.835). An article by Hughes (2006) discusses governments not funding a drug for a rare disease and leaving the patient untreated, compared to treating the patient and the opportunity cost to other patients as a result. He writes, "This contraposition raises important questions on equity, and goes to the heart of what is considered to be socially just" (p.315). There has been extensive academic writing around Pharmac and medicines for rare diseases, however, with so many new decisions being made over the last five years there is a gap in the literature to an extent.

Previous journalism on drugs for rare diseases

There has been much media coverage of Pharmac funding and drugs for rare diseases both in New Zealand and overseas. This has provided the format for the discussion of such issues in the public sphere. Previously, there has been wide coverage in New Zealand of Pharmac's funding of Herceptin. In 2008, the government over-ruled Pharmac to allow women with breast cancer eligible for Herceptin 12 months of the drug, opposed to the nine week trial Pharmac had recommended. The story gathered national attention which many claimed was the catalyst for the government's intervention (TVNZ, 2008; NZPA, 2008). Recently within New Zealand much has been reported about the drugs: Soliris for PNH and aHUS (Johnston, 2013; New Idea, 2012; Mays, 2012), and Myozyme for Pompe Disease (Moir, 2011; Boyer, 2012; Radio New Zealand, 2012). Both drugs have been denied funding by Pharmac and the subsequent stories have mainly used one person to illustrate the issue and in many cases that person appears to speak on behalf of all affected patients. Another story which gathered attention recently is Pharmac's approach to funding medicines for patients with multiple sclerosis after professional rugby player Tim Bateman went public with his family's decision to move to Japan to seek early treatment for his wife. The story gathered attention just before World Multiple Sclerosis Day 2014 and appeared across many platforms (Campbell Live, 2014; Stewart, 2014). While there has been a lot of media coverage of each individual medicine, there

appears to be far fewer stories which focus on the health policy around Pharmac funding. Two examples of stories that do are from the *Sunday Star Times* (2008) which looks at 10 medicines kiwis cannot have and a story by Macdonald (2011) which investigates what Pharmac does and how it makes decisions. Internationally, there are plenty examples of similar stories to those that have appeared in New Zealand about very expensive drugs that other countries have refused to fund (Chu, 2014; Lamperd, 2014; Smith, 2014). In some of these examples, governments did fund the medicine after the story was published. While the impact of Pharmac decisions on patients has been well covered by New Zealand media, there has been significantly less discussion around Pharmac decision-making policy.

Importance of health reporting

Several studies (Schwitzer, 2004; Schwitzer, 2009; Furlan, 2012) argue readers often make important health care decisions based exclusively on the information provided in news stories. For example, Furlan (2012) described how in 1998 a highly respected medical journal, *The Lancet*, pushed an article about the Measles, Mumps and Rubella vaccine and in a subsequent press conference an author of the article inferred a link between the vaccine and autism in children. This was widely, though not entirely accurately, reported in the media and resulted in the rate of immunisations dropping while cases of the measles spiked (p.103). A landmark study by Ramsay, Yarwood, Lewis , Campbell and White (2002) found empirical evidence that parents' lack of confidence in the vaccine coincided with the negative media attention. This empirical evidence gives validity to the claim of Schwitzer and Furlan. Furlan's study follows on from the work of Bedford and Elliman (2010) who called the situation a "debacle" (p.271). Bedford and Elliman went on to argue that while the media fuelled the flames of the issue, medical practitioners often a showed lack of desire to engage in the public debate. They said that while the media gave too much validity to the claims of a link between the vaccine and autism, the medical community did not voice the truth strongly enough. Furlan (2012) writes, "This case illustrates the inherent complexities in reporting medical news to the public who can be swayed to change health behaviours as a result of media attention. It also demonstrates that trust is a construct which takes years to nurture yet can immediately fracture" (p.103).

A study by O'Keefe (1970) on doctors' interactions with medical news in the mass media hypothesised doctors would have a positive attitude towards it. He thought doctors would welcome better informed patients and would use the media as a tool for learning about new procedures. This, however, was not the case, with most doctors dismissing the mass media as inadequate and inaccurate, though they generally acknowledged it was of some use to patients. However, an empirical study in the *New England Journal of Medicine* two decades later found when research was written about by the mass media, in their study of the *New York Times,* it increased subsequent

coverage in the scientific literature (Phillips, Kanter, Bednarczyk, & Tastad, 1991). The study found in the ten years following publication the research published in the New York Times received a disproportionately higher number of citations in scientific literature. Phillips et al (1991) writes, "The effect was strongest in the first year after publication, when Journal articles publicised by the Times received 72.8 percent more scientific citations than control articles" (p.1180). While some medical professionals may not have a positive attitude about health reporting, it still eventually permeates into what they are learning themselves.

It is the opinion of Schwitzer (2009) that in some cases, the mass media's influence is so strong that it can act as a secondary marketing tool. He writes, "We do, though, indirectly help market them [medicines] by the kinds of stories we write, which can stimulate demand. Stories touting the benefits of the latest gee-whiz drug, coupled with ads by the drug maker, are powerful stuff" (p.2). Brownlee (2006) writes, "In simply reporting each newsworthy finding in the professional journals, the lay press has helped sell medical products and procedures to a public eager for good news about their health" (p.156). The influence of mass media marketing is reinforced through the example of the Measles, Mumps and Rubella vaccine. As the study by Ramsay et al (2002) found, the negative media attention of the case had a direct impact on the demand for the vaccine. While the mass media is an important tool for disseminating information about health, journalists have a huge responsibility to readers because of the weight they place on the information provided to them by the mass media.

Difficulties covering health reporting

Much has been written about the difficulties and criticisms of journalists covering health. These range from scientific journalists being criticised for conveying speculation as fact e.g. in the case of global warming and in the case of immunisations (Glazer, 2013), to health reporters being relegated to the role of cheerleader for the medical industry (Abramson, 2009). Although health issues are widely reported in the media, they are often criticised for being speculative, inaccurate and misleading (Larsson, Oxman, Carling, & Herrin, 2003). Glazer (2013) criticised journalism for lacking the rigorous peer review process of scientific publications, because the "journalistic review process serves the goal of generating "news" for a hungry market place of ideas" (p.34). While his argument is true in that journalism does have a different editing process to scientific publications, he fails to identify why the different editing processes are necessary. Larsson et al (2003), on the other hand, found mass media as a whole lacked time and knowledge to edit stories in the same manner as scientific publications. According to Cropp (1997), reporters covering science and medical issues have to remember that nothing is ever simple. She writes, "The fact is most issues are not black and white and it is misleading to represent them as such" (p.23). Cropp explored the difficulties facing

science journalism from the perspective of an investigative journalist. Though her thoughts are valid, investigative journalists traditionally have more time to spend looking at the grey areas of a story while, as Larsson et al (2003) noted, most other journalists do not have that luxury. Their study of experienced medical journalists in 27 countries found nine barriers to improving the informative value of medical journalism, with the most significant being lack of time, space and knowledge. While there are a lot of valid criticisms of journalists covering health, there are also a lot of practical limitations on reporters.

Translating medical jargon

One of the reasons behind claims of inaccuracy in health reporting often stem from the fact journalists are dealing with medical jargon from a field which they are most likely not trained in. According to Mencher (2011), journalists take on the responsibility of informing people about the world around them so that people can act on what they read, see and hear. He goes on to say these actions depend on clear, understandable, and accurate information, though like Glazer does not delve into some of the increasing limitations on reporters such as time and space. Scientific journalism has been tasked with interpreting information to make it interesting and understandable to readers (Glazer, 2013). But as Sekorkin and McGregor (2002) note, you cannot be an expert in every field. Though they were discussing general reporters, this is also true for health and science reporters who, for obvious reasons, are not all going to be experts in pharmaceutical spending or molecular biology. According to Burkett (1986), dealing with this kind of complex information will never be easy. He writes, “You are not a doctor and will not be making diagnoses. You only write about disease. You are seeking to communicate as accurately as possible what medical authority tells you” (p.113). Interpreting the jargon of what the medical authorities say is one of the barriers to medical reporting according to Larsson et al (2003). They found, “Lack of training in critical appraisal and translation of scientific jargon have been reported as factors that limit the scientific qualities of medical reporting” (p.324). While the work of Mencher (2011) and Glazer (2013) holds reporters accountable for an incredibly high standard of science journalism, Larsson et al explores why complex stories too often to result in inaccuracies. Health reporters often struggle to find a way to communicate complicated information in a simple but accurate way.

General reporters covering health

General reporters who have to cover a health story often struggle because of their lack of previous knowledge on issues. Schwartz (2002) explained that there are more specialised reporters than ever before because there is a need for the expertise they can give to their chosen area. He noted, “It is a necessity. Imagine, for example, sending a general assignment reporter to write a story about the national budget” (p.73). While Schwartz engaged with the idea that general reporters can bring a

new perspective to issues, he dismissed their lack of knowledge as being too limiting. Blum (2006) noted that specialising allows journalists to build on accumulated knowledge, rather than researching a new subject for each assignment (p.152). But even specialised reporters can struggle to understand their fields of journalism. Larsson et al (2003) were surprised by the number reporters in their study who said they felt they lacked knowledge despite the fact they were all experienced medical reporters. They explained, "The steadily increasing flow of information in the medical field, the breadth of information that journalists must cover, and difficulties finding reliable sources could explain this" (p.329). While Schwartz (2002) heralds specialised reporters as the epitome of knowledge, the findings by Larsson et al (2003) show even incredibly experienced reporters can feel out of their depth in their chosen field of journalism. While general reporters can enjoy variety in their position, they can also be naturally daunted when encountering a story from an unfamiliar field.

Reporting on health policy

Stories that cover health policy such as Pharmac present their own set of barriers to reporting, largely due to the fact they strongly intersect with political reporting. A study by Briggs and Hallin (2010) looked at the subjects of health stories that appeared in the *San Diego Union-Tribune* over a seven month period in 2002. They found 26 percent of the stories were about policy issues such as hospitals, the health-care system, and public health policy, and enforcement (p.153). These policy issues are often what link health reporting to political reporting. Briggs and Hallin go on to say that some of the health policy stories they found were indistinguishable from other forms of political reporting. Therefore, not only do health reporters have to be knowledgeable about their specialisation, they also have to know the political circumstances and ramifications of what they are reporting on. As Briggs and Hallin concluded, "few topics are more political" than health reporting (p.150). According to Graber and Dunaway (2015), investigative journalism stories no matter the subject often result in policy consequences (p.147). When the topic is about policy in the first place, such as health policy, an investigative piece would therefore be even more likely to result in policy consequences. According to Young (2011) politicians can be a barrier to reporting on policy. In the case of the 1996 election in Australia, journalists were sometimes only provided with detailed policy documents minutes before an interview was to be conducted or a story to be filed (Young, 2011, p. 141). While there is a strong intersection between health and political reporting that can create barriers for journalists, it also means health reporters have the chance to influence and inform policy at the highest level.

Investigative health reporting

Increasingly, there is a need for more investigative health reporting as medical science has become more difficult to report on because of changes in the health industry. More than ever before, medicine has become political and commercial (Brownlee, 2006). According to Abramson (2009), the fundamental purpose of medicine science has transformed from being a public good supported mainly by public funding into a commodity for commercial profit. He writes, "When it comes to real-time reporting on medical science, journalists (as well as many experts and even medical journals) have been largely relegated to the role of cheerleading for the industry, unable to fulfil their rightful role as critical investigators providing a balanced view" (p.1). Abramson goes on to argue that because the fundamental mission of commercially based science is to make a profit, more than ever before medical reporting requires an investigative approach. Schwitzer (2009) agrees, saying that while there are some good health care stories, they appear less frequently than is necessary and possible. He writes:

> When news reporting is seen as trumpeting new treatments, tests, products or procedure, and it is done without applying watchdog oversight, then the news consumers get will be along the lines if what Bartlett described [daily health reporting that lacks critical investigation]. When reporting about health is seen, instead, as the exploration of evidence, cost-effectiveness, comparative treatments, medical technology assessment, access to medical care and disparities in care, then the news we read, see and hear will be very different" (p.2).

Both Schwitzer and Abramson appear to agree with earlier claims that health reporting has become speculative, inaccurate, and argue it is not critical enough. As mentioned previously, science journalists have been tasked with taking very complex information and relaying that to the lay public. However, Regalado (2006) argues that journalists need to be focused on being more critical as it will improve society. He writes, "The fact is most science journalists are concerned with explaining science to a general audience. Reporters take difficult material and present it in a way that lay readers can understand. With so much of modern life based on science, explaining it clearly is probably our community's most important objective. But sometimes we science reporters can get a little complacent" (p.119). Brownlee (2006) agrees and argues that it is not the role of reporters to "trumpet every tiny advance but to shine light into the dark corners where big business and medical science intersect" (p.160). While it is a nice sentiment, this can sound like "mission impossible" to journalists these days according to Abramson (2009). These academics agree there needs to be a push for more investigative health reporting, though none suggest the best way to go about this.

Phone and email interviews

An integral part of journalism is the human interaction between reporters and sources. One of the most difficult barriers to bridge when building rapport is that of phone and email communication. Unfortunately, face-to-face communication is steadily becoming a less common method used by journalists according to Sedorkin and McGregor (2002). They argue this is mainly because of increasing time pressure on reporters. They also argue the difficulty with phone interviews is there is not the advantage of non-verbal clues, while email interviews are not spontaneous and can lack colour. Huff (1997) manages to find some positive in the new technology, arguing it helps journalists to receive story tips and press releases via e-mail, locate a vacationing source across time zones, set up interviews and double-check facts. But she too agrees that face-to-face communication is best. She explained, “When you want stories, you want people to be talking to you. People online are terse. People in real life are storytellers". This is reiterated by Sawatsky (2002) who said an email interview is not an interview at all because you are just waiting for a response and in his view just a response does not constitute an interview (as cited in Hart, 2006). The theme of the literature appears to be that while journalists should utilise phone and email it should never replace face-to-face interviewing.

Interviewing figures of power

Once a reporter has researched a story, there is normally a figure in power that needs to be interviewed, especially when it comes to reporting on policy. Cropp (1997) argues these people are often well media trained and used to dealing with tough questions. Because of this, she says it is important not to interview them too early, as the reporter could neglect to ask vital questions and overlook the significance of certain answers. Cropp’s argument is valid in the case of investigative journalism as most of the research is likely to have been uncovered before approaching, for example, the company or government department the journalist is writing about. She assumes that once you have interviewed them, therefore tipping them off about what you are writing about, the reporter will not be able to approach them again. However, she does not take into account the fact that the organisation may be willing to have continued lines of communication, especially if it is for a feature article, a story of significant public interest or a story that is continually developing. When it comes to the interviewing these people, Cropp states:

> Journalists sometimes argue that they do a better job by NOT knowing much about a topic because it helps them to ask the sorts of questions the average person in the street will wants answered. Don’t kid yourself. Imagine being an interviewee faced with a reporter who displays almost complete ignorance of the topic in hand, then has the arrogance to say it’s an

> advantage. Why put yourself out for someone who can't be bothered making the effort to do some basic homework? (Cropp, 1997, p. 39).

She argues planning an informed question line that will get you the answers you need is even more important in interviews with people in power. She also argues that people who specialise in a topic have little time for ignorant reporters, a claim that is echoed by Mencher (2011) who argues sources respond to interviewers they consider competent and trustworthy. According to Ullman (1995), even before the interview the reporter should be well-versed in the subject. The consensus of these academics appears to be that reporters need to be well prepared before interviewing anyone, but particularly figures in power, who often tend to be the pivotal player in a story.

Public relations

Often before an interview even takes place, journalists encounter what can be a difficult barrier to reporting; the public relations officer. The relationship between public relations and journalists has always been tense with reporters sometimes viewing public relations as unethical, manipulative, one sided and deceptive (DeLorme & Fedler, 2003, p. 99). On the other hand, journalists can view public relations solely as being paid to put a positive slant on issues involving their client to the detriment of accurate reporting (Cropp, 1997, p. 20). Cropp goes on to argue that though public relations officers can be useful for quick background information and understand the drawbacks of saying "no comment", reporters must remember that often the negative or unflattering information is being omitted (p.21). According to du Frense (1995), the employers of public relations officers expect them to orchestrate news to their advantage and disguise or play down potentially embarrassing information (as cited in Sedorkin &McGregor, 2002). Because of this, public relations officers are defensive when dealing with media because of this circle of distrust between the professions (Kopenhaver, 1985). Journalists then view public relations officers as making their job more difficult, though the animosity goes both ways.

These frictions centre around the idea that journalism and public relations serve two different purposes. The two professions have different and often incompatible goals (Furlan, 2012). According to Kopenhaver (1985), the hostility between the professions begins at a classroom level and is filtered through into the workplace. She describes how journalists are taught, either at a university level or early in their career, to hate and reject news releases (p.34). Shaw and White (2004) agree, saying the prejudice against public relations is rooted in journalism culture. Their study questions the validity of having the two professions within the same school at a university level. But despite the hostility, the two professions are dependent on one another. Reporters need public relations officers

to get access to sources and public relations officers need journalists to get information concerning the pubic into an area they will see it. Though there is a state of distrust between the two professions, that does not necessarily prevent collaboration (Furlan, 2012, p. 112). Furlan explains, "One can therefore extrapolate that the professional norms of truth-telling and fair, balanced, critical reporting in journalism remain intact if distrust is present" (p.112). While the relationship between journalism and public relations could be improved, perhaps with better understanding of each other's roles and goals, it does not prevent collaboration that is on some level successful.

Non-profit organisations

Non-profit organisations, and lobby groups, often provide journalists with story ideas, balance in an article and add a necessary human interest element. However, like public relations officers, these groups have a vested interest in a topic. In the study by Larsson et al (2003), health reporters listed lobby groups wanting to promote certain ideas or a special issue alongside public relations officers as obstacles to accurate reporting (p.326). In the end, every organisation has its reasons for wanting to be published whether they want good publicity for accomplishments or are issue-orientated (Blanchard, 2006). It is the view of Cropp (1997) that, "Lobby group experts make good "smoke alarms", but remember they are working to an agenda so always double-check their claims through other sources" (p.21). Brownlee (2006) noted how non-profit organisations and lobby groups can also have connections with drug companies resulting in incredible bias. She writes, "These days you can never be sure which ones are truly grass-roots organisations that are acting as watchdogs on behalf of patients, and which ones are "astroturfs," which are created by industry to help market a disease" (p.159). Brownlee points out that sometimes the funding of these non-profit organisations comes from drug companies. Because of the vested interest these groups have in a topic, journalists should look into their background and any claims they make. Though these groups may appear well intentioned, they also have an agenda.

Interviewing the vulnerable

Vulnerable people, such as the sick or marginalised, are one of the most difficult groups for journalists to interview. People such as the disabled, mentally ill, homeless, traumatised, poor, unemployed and illiterate are in an on-going position of disadvantage and therefore in a constant state of vulnerability (Richards, 2009, p. 18). According to the Association of Health Care Journalists (2004), special considerations should be made for these groups (as cited in Schwitzer, 2004). The association outlines that journalists should always use sensitivity and understand legal limits when dealing with children, mentally handicapped and inexperienced sources. They write, "Always consider alternatives that minimise harm while making accurate reporting possible. Show respect. Illness, disability and other health challenges facing individuals must not be exploited merely for

dramatic effect" (p.11). Hollings (2005) wrote that when New Zealand reporters travelled to Asia to cover the 2004 tsunami it raised the ethical issue of to what degree should they intrude upon the grief of survivors. He noted studies which show journalists can have either significant positive or negative effect on victims' recovery from mental trauma, depending on the approach taken. He described how a psychologist working in Phuket since the tsunami said five or six children who lost parents were repeatedly interviewed and have since become numb to their feelings because they had to repeat their experiences in superficial interviews, not allowing them to fully work through their feelings. Hollings interviewed 13 journalists for the study, although he did not report on what kind of considerations they made when interviewing the vulnerable. While CEOs and prime ministers are media savvy it is different for ordinary citizens, let alone the vulnerable, who have no understanding of the conventions of journalism (Richards, 2009). According to Richards, it is the responsibility of the journalist to minimise harm to the subject to the greatest extent possible. He writes, if harm does occur as a result of reporting journalists should be able to justify it in ethical terms, though he does not specify what these ethical terms could be. Richards writes, "When dealing with society's most vulnerable, journalists are walking a tightrope between reporting as comprehensively and accurately as possible and treating their news subjects with respect and dignity" (p.15). Journalists typically have to wrestle for power in interviews, particularly with people who are used to being in positions of power such as politicians, sports stars or business tycoons. But when it comes to interviewing vulnerable groups within society it is the journalist that has to power to not add any extra grief, public embarrassment or trauma to their lives.

Discussion

This study sought to understand some of the difficulties around health reporting with reference to Pharmac's approach to funding drugs for rare diseases. Following on from the literature review, this section will examine and discuss the work of academics in reference to my experience undertaking the long-form journalism article.

Through undertaking this investigation I had the opportunity to explore the issue of Pharmac funding of rare diseases over an extended period of time. This meant I did not encounter some of the barriers to reporting outlined by health reporters in the study by Larsson et al (2003). In that study it was found journalists struggled with time to research and write a story, limited space to write it in and knowledge on the issues. However, I was given five months to research and write the story, 5000 words to write with and enough time to acquire the necessary knowledge on the topic. Academics argued the nature of daily journalism means stories are often not developed to the full extent, sources difficult to find are often not followed up with, and information given by seemingly well intentioned non-profit organisation is often not double-checked. It is my hope that through the long-form journalism I was able to develop the story in a meaningful way not possible through daily journalism. I was able to follow up with difficult sources, some which took weeks to get back to me, and fact check the information I was given. I would equate my experience as being similar to that of an investigative journalist. Cropp (1997), an experienced investigative journalist, wrote that most issues are not black and white and to represent them as such is misleading. Going into the study I aimed to use this opportunity to facilitate the discussion around the issue of rare diseases in New Zealand and to delve into some of the grey areas of the topic. An example of this was the idea that if the drugs for rare diseases were funded this could mean Pharmac may not be able to fund some drugs for less rare conditions. This was an issue not developed fully in most previous reporting on the topic. This study gave me the opportunity to explore a complicated issue in incredible depth, an opportunity increasingly denied to journalists.

As outlined in the literature review, academics have described health reporting as one of the most complex areas of journalism. My experience undertaking the long-form journalism has proven this to be true, particularly because of the medical jargon involved. While writing about the symptoms of rare diseases and the clinical trials of the drugs that target them, I identified with Mencher (2011) and Glazer (2013), who said journalists have been tasked with interpreting this information for readers. But because I was not a doctor, or a health reporter, I struggled to make sense of what I

was reading. To then attempt to convey the information to readers, in a way they could understand, was a challenge. Other challenges were understanding the background of the issue, how Pharmac worked and how funding of rare diseases happened in other countries.

My experience has led me to agree with Schwartz (2002) and Blum (2006) that when it comes to health reporting specialised reporters are necessary because of the accumulated knowledge they have. I would equate my experience as being similar to that of a general reporter sent to cover an incredibly complex topic they had not reported on before. While reporters should have a good general knowledge, often health reporting requires an in-depth knowledge of a topic (Larsson et al, 2002). Had I been a seasoned health reporter who had previously covered Pharmac, or perhaps some of the drugs I chose as case studies, I estimate my research time could have been cut in half. However, I do not think my investigation was worse for my lack of background knowledge. While it took me longer to investigate the story than it would have taken a health reporter, it did not limit the quality of the investigation.

Because my long-form journalism was a story that affected people in all parts of New Zealand, it meant I was not able to interview every subject in person, because of both time and money. Most often I spoke to people on the phone and occasionally on Skype. Huff (1997) stated, that there are some benefits to phone and email communication, but face-to-face communication is generally preferable. I found this to be the case through my long-form journalism article because a lot of what I was discussing with people was very sensitive information. Some of the benefits of using phone and email for this investigation included being able to get in contact with people overseas, set up interviews in advance and have facts double-checked. Sedorkin and McGregor (2002) found it is important for sources to be able to trust the reporter and building rapport is much easier in person when you can use body language and clues in the surroundings to build up that relationship. In the case of the patients with the rare diseases I believe there would have been more of an emotional connection with them if I could have interviewed them in person. For example, perhaps they may have seen in my facial expression that I was listening to what they were saying or that I empathised with their situation. Often they had been interviewed before and calling on the phone possibly made them feel as though I was just another reporter. With a face-to-face conversation they may have felt more comfortable with me and therefore given better quotes or details that perhaps they had not given to other reporters. However, sometimes even a phone interview is not possible. Sawatsky (2002) said an email interview is not an interview because you are just waiting for a response. During my investigation I wanted to interview the Minister of Health, Hon Tony Ryall. After speaking to his office, I was asked to send a brief email to his press secretary outlining what it was in regards to.

After doing this, rather than setting up an interview, I received a brief, and very generic, statement from Mr Ryall in response. I attempted to get back in touch with his office for a phone interview but in the end had to settle for the statement. As outlined by Sawatsky, email statements can lack colour and spontaneity, which perfectly sums up Mr Ryall's response. I did not end up using the statement as it did not add anything new to the discussion. While I agree with the literature that says to steer away from anything but face-to-face interviews, I found sometimes it was unavoidable.

There is a lot of literature which outlines the tense relationship between journalism and public relations (DeLorme & Fedler, 2003; Cropp, 1997; du Frense, 1995; Kopenhaver, 1985). But while undertaking this investigation I found public relations officers to mostly be approachable and willing to facilitate the discussion of my investigation. I was initially apprehensive about approaching Pharmac's public relations officer. I was concerned I would be questioned about the topic of my investigation and possibly having access to the people I wanted to interview limited or even denied. From my point of view, this came from previous experiences I had with difficult public relations officers. It also came from what Shaw and White (2004) described the prejudice towards public relations that is rooted in the journalism culture. The public relations officer for Pharmac was helpful in setting up an interview with the appropriate person and communicated with me efficiently. He was in the room during the interview but rarely interrupted and when he did was mainly to help clarify something for my investigation. While public relations officers do have to protect the interest of their client, following my experience I agree with Furlan (2012) that though both sides do not entirely trust each other, this does not prevent cooperative collaboration. While there may be some difficult public relations officers, continuing to circulate the idea that they are the enemy in the end will not benefit journalism as a whole.

One of the most daunting interviews I undertook while working on the long-form journalism was with Pharmac director of operations Sarah Fitt. It was Mencher (2011) who said interviewees responded to reporters who they viewed as competent and trustworthy. I knew that in order for Ms Fitt to view me as competent it required being well informed about the topic before I went into the interview. I also knew that, as Cropp (1997) explained, people in Ms Fitt's position are likely to be media trained and used to dealing with tough questions. As Cropp suggested, I interviewed her after I had researched the topic well, which in my case took a number of months. My experience from both this study and previous work has led me to agree with Cropp, that interviewees do not respond to a reporter who is purposefully ignorant. Ms Fitt responded openly to me because I presented myself as competent and worthy of her time. When I interviewed Ms Fitt I was well prepared with a list of questions but did not restrict myself to that list she mentioned something relevant to my

investigation. Because she was extremely busy I tried to keep my questions succinct to maximise the time I had with her. While the interview was daunting, I believe I won the trust of Ms Fitt who allowed me to contact her with follow-up questions.

In my experience of undertaking this investigation I found non-profit organisations to be well meaning and helpful, but with their own motivations. I agree with the literature as a whole which generally argued that like public relations, non-profit organisations worked to their own agenda (Larsson et al, 2003; Blanchard, 2006; Cropp, 1997). For example, when interviewing NZORD their interpretation of a decision from the Ombudsman was that it was criticising Pharmac, but after reading the decision myself I did not think that was entirely the case. Part of NZORD's agenda is to raise awareness of medicines not available in New Zealand for rare diseases, therefore they are naturally very critical of Pharmac. Another example of having to be critical of non-profit organisations was the PNH foundation which I discovered were partially funded by Alexion, the drug company which supplies Soliris for PNH patients. While I had assurances from Mr Webby the Foundation was entirely independent of Alexion input, it is in the interest of Alexion for Soliris to be funded in New Zealand as they would make millions of dollars. This was outlined by Brownlee (2006) who said non-profit organisations can sometimes be used by drug companies to help market their product. In fairness to the PNH Foundation, their website does openly outline the Alexion's financial contribution. After some investigation I found Alexion had provided funds for similar non-profit organisations overseas (Hutcheon, 2014). Though non-profit organisations are excellent to alert the media of issues and were incredibly helpful for my study, from my experience of this investigation it is important to remember to be critical as they will their own agenda.

Academics agree that journalists hold a lot of power when interviewing the vulnerable, such as the sick and marginalised. The patients I was interviewing had rare diseases and had been marginalised within society after Pharmac refused to fund medicines for them. Quite often they were very sick, with one woman having to take off her full face mask of oxygen even to speak to me. I agree with Richards (2009) that it is the responsibility of the journalist to ensure the protection of vulnerable interviewees to the greatest extent possible. When interviewing the woman with the oxygen mask I kept my questions concise and asked her to tell me if talking got too much for her. The Association of Health Care Journalists (2004) said special considerations should be used for these groups. In the instance of interviewees with rare diseases that meant showing sympathy, patience and respect if there was a particular issue they did not want to discuss. While it would have been appropriate for me to put pressure on the Pharmac director of operations, Sarah Fitt, if she refused to answer a question, it would have been cruel to do that same with those patients. The patients with rare

diseases were vulnerable because they were sick and therefore I had a responsibility not to further impact upon their lives in a negative way.

While most academics have argued for more investigative health reporting, my experience in writing the article about Pharmac shows investigative health reporting requires significant amounts of time and knowledge. I spent five months researching, reporting on and writing about Pharmac's funding of drugs for rare diseases. In spite of that I still feel as though there is more work I could do on the topic. Academics such as Abramson (2009) and Brownlee (2009) argued because the medical industry is becoming increasingly commercial and political there is an increasing need for more investigative journalism. The evidence of my investigation has shown this to be true and only through taking on an investigative story, such as the one I produced about Pharmac, could an article of substance be produced. However, following the investigation I am now aware of the kind of time and knowledge it takes to produce piece of investigative journalism on a health subject. My goal of the long-form journalism was, as Abramson noted, to be a critical investigator providing a balanced view. I believe I attained this but only because I was not confined to the restraints of daily journalism. In retrospect, I am not surprised by Schwitzer (2009) who said good health stories appear less frequently than is necessary and possible. I think that while increased, robust health reporting should be the goal there are certainly an increasing number of barriers to getting there.

Conclusion

This study has illustrated that the media is an important part of how society makes decisions about their health, for example: what medicine to buy, which immunisations to give their children, and what drugs trials can be trusted. The articles produced in the media may be the only source of health information the public has unless they go to their doctor for advice. The example of the Measles, Mumps and Rubella vaccine showed a direct correlation between what the public read and their medical decision making (Ramsay et al, 2002). Similarly, the media is used by medical professionals (Phillips et al, 1991) and policy makers (Briggs & Hallin, 2010)to inform their decision making. It is for this reason that journalists have a responsibility to produce well informed, accurate, critical and readable stories.

This study argues that there are many barriers to health reporting including communicating the complex nature of health stories to the lay public, medical jargon, reporter's lack of knowledge, and the agendas of public relations and non-profit organisations. The long-form journalism, on Pharmac funding of medicines for rare diseases, showed reporting on a national story from one location and interviewing the vulnerable to be barriers also. This is coupled with the already increasing pressures on journalists to produce more content faster than ever before.

A major conclusion of this study is there is a need for more investigative health reporting, but it is becoming increasingly difficult to write such stories to the standard required. The need for more investigative health reporting derives from the fact the health industry is becoming increasingly commercial and political (Brownlee, 2006). Academics agree it is the responsibility of journalists to investigate this industry, perhaps more critically than ever before. But with the increasingly apparent barriers to health reporting outlined above, it is easy to why Abramson (2009) said investigative health reporting can seem like "mission impossible". Though it is beyond the scope of this study, it would be good to look into how investigative health reporting could be improved from within the journalism industry. It is my belief that reporters, particularly health reporters, would like to do more investigative health stories but perhaps do not have the time, encouragement, resources or knowledge to do so.

Another major conclusion of this study is that while Pharmac has attempted to widen access to medicines for rare diseases, through its newly established contestable medicines fund, New Zealand patients are currently more disadvantaged than their counterparts overseas. If the patients with rare diseases interviewed for this study were born Australia or Scotland, many would already be receiving treatment. In many ways Pharmac has been a huge success through its ability to drive down the

price of pharmaceuticals and overall Pharmaceutical expenditure. But in the case of drugs for rare diseases, Pharmac appears to be trailing other parts of the world. This has resulted in a small number of New Zealanders who have been denied funding for medicines, which could possibly save or prolong their lives. While the contestable medicines fund may mitigate the issue to an extent, it will not happen overnight. Furthermore, it still does not change the criteria which have marginalised those people with rare diseases.

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