Medical Snapshot System

Explanation, Discussion and Proposal

1st January 2015

Any discussion of fundamental human health and medical matters will be complex, and so is this document. However, specialist medical knowledge is not required to understand what is presented, just patience.

The long-term investment proposal is simple, once even just some of the discussion is accepted. Early stage costings are simple to calculate.

About Medical Snapshots

This concerns a new approach to how health needs are understood and delivered, whether medicine is involved or not. Since 2007 I have sought informal review from practitioners of medicine, law, biosciences, neuroscience, business and more. Now in 2015 I am satisfied it passes the smell test by professionals who face daily the problems it addresses. Many professionals are concerned that medicine is not delivering the level or quality of results it could, and increasing funding doesn't change the fundamentals which limit the results.

This document is a commercial view on medical facts and concepts.

Two limitations:

- Evidence cited is qualitative.
- no formal review, literature review or formal peer consultation.

These are easily addressed, because these topics are the subject of a great deal of quantitative, multiply-reviewed research. This document merely makes a case.

At the broadest level the health and wellbeing issues addressed here are:

1. one of the greatest problems facing humanity;
2. one of the greatest financial challenges for governments and insurance companies;
3. the centre of an ethical logjam in commercial medicine.

That's aiming high but the issues can't be separated.

This proposal also addresses the UN Millenium Goals, the EU's commitment to “improving healthspan by two years before 2020” and other laudable statements by the great and the good.

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Top-level Summary

Fundamental insight: many medical problems come down to the *timing and direction of information flows*. This is a new approach because timing for medical testing is overwhemingly “as soon as possible” (with the exception of followups and a few very specific types of preventative screenings), and the only direction of flow has been towards the patient.

The proposal: a self-funding and immediately feasible method to improve results and decrease costs in medical systems.

What is involved: a novel view of existing incentives for collecting detailed medical information using modern technology, together with a modified ethical and legal approach.

Is it practical? : All components of this approach exist and the problem space is well-recognised, so nearly 100% of the work required is about different and arguably better-quality thinking.

Problems and Caveats: Some of the non-technical dilemmas raised may have no solution. The new methods of thinking proposed may be too difficult for governments to accept. Drug company enthusiasm might be hard to contain, despite the careful design presented here.

Summary

Two very difficult health problems are addressed:

1. When an individual has a disease or health anomaly we want to notice early and treat with maximum intelligence *however* there are many issues connected with early detection

2. Medical science is ignorant in many fields because good empirical evidence about populations either has not been collected *or* there are ethical and practical barriers to doing so.

Addressing these two problems requires a modification of existing medical, legal and ethical information gathering frameworks.

Incentives and ethical rules are created so that people (whether with a diagnosed condition or with no health anomalies at all) can choose to sign a contract for regular, broad-spectrum, highly accurate medical testing. The testing organisation has funds to uphold only two duties of care to the individual, but will uphold them to an extreme degree:

- make the testing as close to zero-impact as possible using safe, largely non-invasive, mostly telemedicine techniques, ("**zero impact testing**") and,
- deny access to all information regarding the tests results, tests and methodologies to all parties including the individual, even very general questions ("**zero information leakage**")

These duties of care are core to this proposal.

There is no other duty of care. That's a radical statement in medicine, and can only be ethical because:

> *The individual's medical care regime is unrelated to the testing.*

No change in medical care: Whatever the individual normally does for her health will continue unaffected by the Snapshot System. To the individual, they might as well be attending a knitting workshop once a month as interacting with the Snapshot System. Except they are getting paid.

Full access to normal records: The individual authorises the testing organisation to have full access to normal medical records held by their normal doctor without further reference to the individual. Most jurisdictions have a legal mechanism for this, used by insurance companies, courts and more.

Nature of tests: Testing would be both physiological and otherwise (e.g. interviews), and ideally the last tests would be during clinical autopsy (i.e. after death).

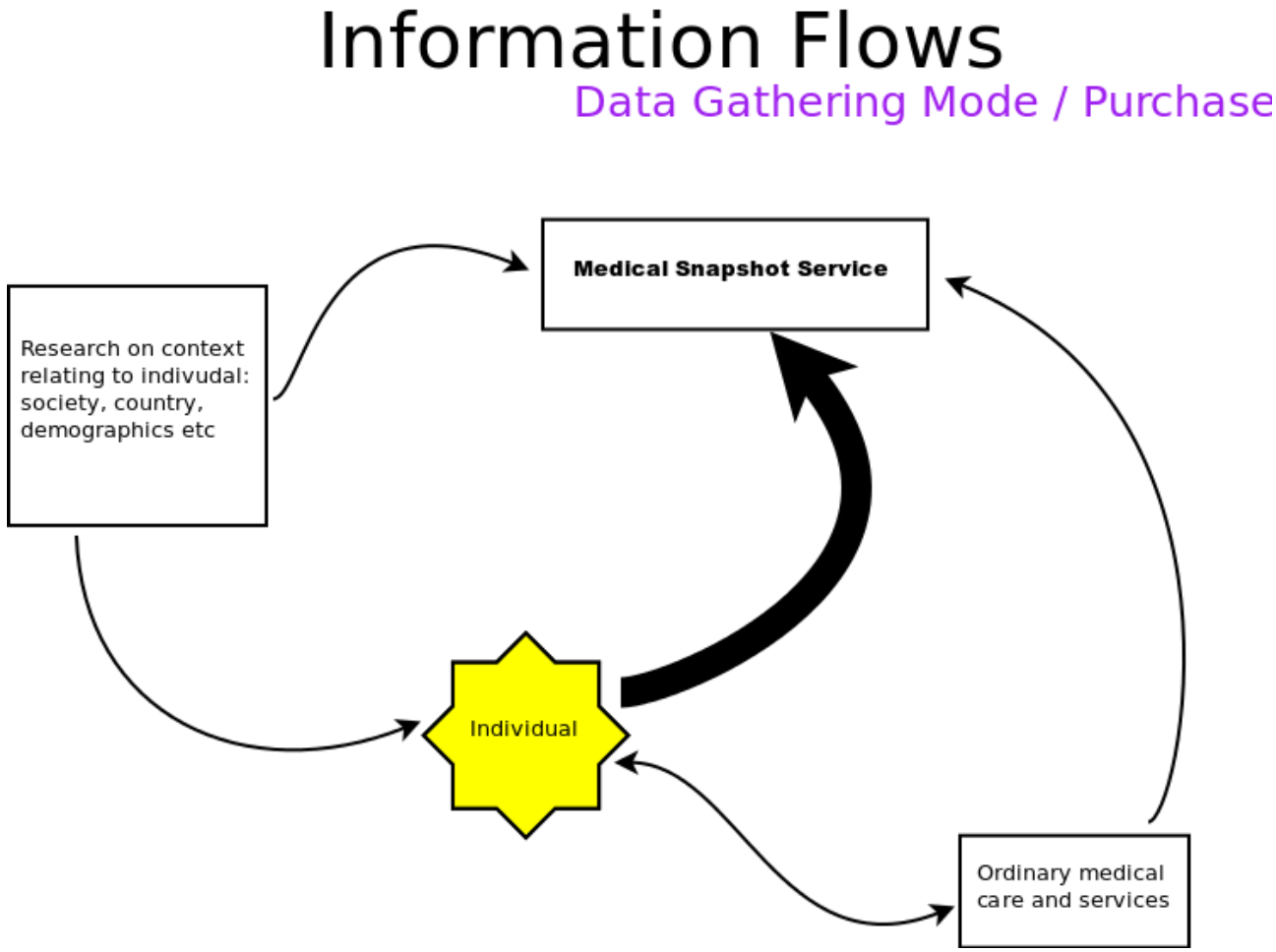
A major human interaction problem: The second duty of care is going to be difficult to explain to people, particularly in the emotive situation where they have become ill and then discover that the Snapshot service probably knew about the illness long before their doctor. **This is why the payment helps**, because it makes a psychological statement about fee for service and a completed transaction. We don't expect a carwashing service to notify you about rust in your car.

Summary from the individual's point of view: It is a personal medical time machine they are paid to create. When the doctors who see the individual normally have evidence of a sickness, the individual may request access to medical history. The testing organisation may (and in most cases, will) issue a background report that specifically addresses the evidence submitted by the doctors caring for their patient.The individual has the *advantage of perfect medical hindsight, but not the harmful disadvantage of too much early knowledge*. This addresses the first of the large problems, assuming normal medical care has correctly noticed the sickness as soon as possible..Of course, illness often isn't noticed early for many reasons, and that is something that the long-term evidence from the Snapshot system can be used to improve.But the Snapshot system is still a great improvement on the current situation of hit-and-miss guesswork about the history of an illnes.

Summary from the testing organisation's point of view: It's a long-term large-scale study following a very large number of variables with high frequency and precision, with unprecedented availability of data, of immense value to society and government. This addresses the second of the large problems. It is also of great commercial value to medical and health-related companies conducting their own testing, and the regulatory bodies for such companies. This is where funding comes from to run the tests and pay the individuals.

Summary from a medical science point of view: Reducing medical ignorance requires studies which are not currently ethical, for very good reasons. The ethical way to perform these studies is to be entirely outside the current medical system and to avoid all promise, implication or even hint of performance. This adheres to "*first, do no harm*" in a weakened sense - harm could be done to individuals through not telling them important information, but no harm is actively done. The idea is that the individual will be no worse off than if no tests had been done at all since this is independent of the individual's normal medical services, and that much greater good will be done in the long run by the information embargo. Having dealt with the most significant cause of potential harm, which is expectations associated with testing, there is only the need to minimise risk of physical harm through botched or inappropriate testing. This latter risk is addressed by emphasising high-technology tests with remote reporting as much as possible, risk-averse policies, and avoiding a testing monoculture so that tests can be used to monitor each other for possible impacts.

(several fixes to this sketch required.)



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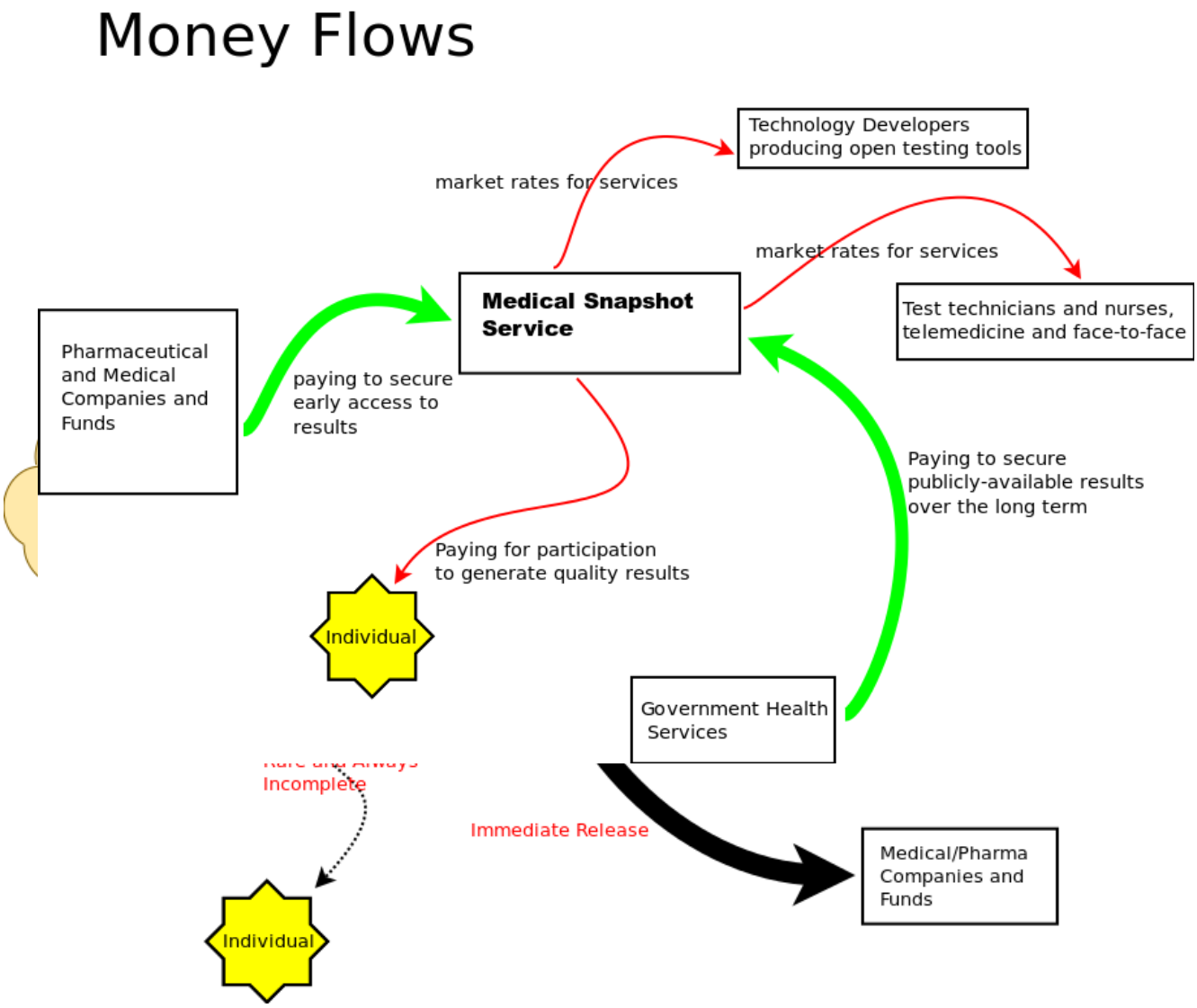

Obvious Questions Answered...

Will the resulting information be proprietary forever, or (equivalently) give rise to patents on aspects of human bodies or other controversial IP-related outcomes?

No.

The context here is that the dataset is (1) of lasting value to humanity and reduction of human suffering and (2) would not exist without purely cash-driven commercial interests being involved. By clever use of time, both these contexts can be fully addressed.

In terms of value to humanity, safeguards will be put in place to ensure that data from the studies are made freely available forever for analysis under a non-restrictive license that also addresses patents. My stock phrase is “access without charge, worldwide, royalty-free, in perpetuity.”

Given the long timescales proposed there is ample room for a time delay for commercial exploitation. Companies have short-term requirements from data that does not conflict with the longer-term interests of most other consumers of medical data. BigEuros Pharma should be encouraged to make money in the three years before a dataset is made public. BigEuros Government will be using this same data (ongoing, as it continues to grow!) for decades in order to save billions.

The goal of this scheme is to make it easier to get lots of observational data collected under controlled circumstances over a long period of time... but isn't this the goal of ordinary medicine anyway?

Yes.

But there's a catch. Yes, this is what all non-emergency medicine tries to do. But in practice it is extraordinarily difficult. Most existing medicine falls dramatically short of this stated big-picture goal, no matter what wonderful small-picture advances are made in solving aspects of human suffering.

If that seems surprising, consider these three practical problems to meeting this goal:

1. Collecting **quality empirical data is difficult ethically, legally and practically**, which is why it is so expensive. Motivations for all parties vary so much that it is difficult to achieve the best desired outcome. Qualified medical practitioners with unimpeachable records and evident motivations related to the human condition can spend years constructing one narrow, five-year study before it is approved. This is not merely inefficient, it is increasing the effect of medical ignorance – yet another tiny island of knowledge is being created in the ocean of ignorance.
2. **Causality is a problem**, when the mere fact of gathering the data affects the subject or the subject's care. This is especially true in the problem of over-testing. This alone makes getting good quality data very difficult.
3. **Ethics related to the individual trump ethics related to universal suffering**. It is not ethical to continue medical observations without intervention when we have information that will or could potentially help the patient. But helping the patient(s) will change or prematurely finish the study (causality again).

Causality – woo. That sounds like Time Travel and Doctor Who!

Quite correct. Whenever we hear the word *causality* there's a good chance time travel can come to the rescue. Lacking magic, we have to use the perception of time travel instead. Computer Science has done this for years, and the same concept is found to a lesser extent implicitly in biology and law. We do this by controlling the manner, direction and timing of information flows.

But isn't this already happening, can't I just go and buy a full personal scan?

Yes, there is already an active industry in many countries for private medical screening instigated by the patient. A small percentage but large absolute number of UK patients are presenting their GP with the results of full reviews, including scans, without a specific trigger. These assessments are commercially promoted - *just £500 for peace of mind*!

As a general solution for society at large this is not a good thing, definitely not. It is deeply flawed (consider the commercial motivations involved, especially in a fully privatised medical system as in the US) but it does establish that there are people who like the idea of pre-emptive information. So yes, among some people there is already an acceptance of the basic premise of this proposal. There is a very large testing industry in US medicine which could probably have its focus nudged by sufficiently skilled marketing, and certainly this is a high value market hungry for new angles.

Any occasional good a "peace of mind" scan might do is counterbalanced by the large potential harm. There is perhaps a case for an ad hoc scan as a tool of last resort for a person with a reasonable belief that their doctors are not making competent investigations. But that is a symptom of a broken system not a general solution – hypochondria driven by untrained people doing their own research on the internet has become a serious and expensive medical problem. Even as well-informed patients increase the quality of their own medical care. It's tricky to get right!

As discussed further below, in a situation where there is a functional medical system people purchasing occasional ad hoc full body system scans are exposing themselves to risk and putting their doctors in an awkward position.

Some UK GPs have told me they have received such scans from a patient, and they address it by saying a few comforting words and then just putting the scans on file. This is probably the best thing they can do, absent glaringly obvious indicators of morbidity. These patients could be getting safer and better outcomes for their money, and in addition helping broader medical understanding, if some version of the Snapshot Service was available.

How can you give guarantees of data security, including against law enforcement requests?

Firstly, it is entirely legitimate to aim to be proof against law enforcement. That is a run-of-the-mill requirement when the best companies develop their security arrangements. It is also a basic tenet of computer security. No doubt this will need to be developed further as the Snapshot proposal matures, but only by applying best practice security thought, no specific or new work is required.

Secondly, while nothing is ever completely secure, Snapshot security issues are in a classic set of problems that technical and legal geeks love working on and for which there are some well-tested solutions already in use. This document deliberately avoids security altogether, for the same reason it avoids medical testing and other technology. Security and technology things are just a matter of engineering.

How can this ever possibly pass ethical review?

We'll never know for sure until it does pass! Three things that suggest it might be reasonable are:

- Many professionals think it is worth a try (anecdotal evidence from my own discussions.)
- There are obvious negative effects on some populations through lack of medical knowledge, for example young sufferers of acute arthritis or Fragile X syndrome. So a restricted version of the Snapshot system aimed at particular populations with known problems is no different from experimental treatments that are often approved by ethics committees except that the Snapshot system is vastly less risky. Narrow applications could still effectively demonstrate the Snapshot system.
- There is a way of testing the Snapshot system on healthy populations without requiring any new ethical considerations by using Chinese Walls. Divide a group the healthcare professionals with full rights to access data into subgroups whose access to the data is artificially restricted. These Chinese walls of information control can be used to simulate a snapshot system to a reasonable approximation within existing approaches. Ethical approval will still be needed as for any normal study, but if the target population of presumed-healthy individuals is carefully chosen – for example, regular blood donors, including the recently deceased – this too will be minimal.

Background

The background is presented as a series of reasonable but disjoint statements. The scheme in this document is justified by building on these background statements without exceeding their scope. Full references are needed for this to become a proposal; for the moment please take statements at face value and focus on the general principles - which are plenty enough to think about to start with!

Statements on Medical Testing and Patient Treatment

Everything in this section is supported by credible sources, often including evidence-based medicine.

The following points illustrate, in a negative way, the problem of causality:

- Many medical conditions are evident in test results long before they become a problem
- Early detection and treatment significantly improve medical outcomes, when the detection is correct rather than false alarm or other misdiagnosis
- Evidence of long-term medical conditions are frequently found in clinical autopsies or CT scans - such as small cancers - that would certainly have triggered alerts and maybe intervention had tests been taken. With the benefit of hindsight we can say testing would have exposed the patient to unnecessary risk.

There is evidence (not cited) that the ready availability of tests can lead to a skewing of outcomes:

- patients can become overly concerned with tests and the results of tests
- doctors and patients can come to depend on tests, or even just the fact that tests are in train, at the expense of other diagnostic or treatment paths
- patients can be subject to unnecessary medical procedures following testing, either due to their own anxiety or the anxiety of doctors
- doctors' anxiety may related to risk factors for the doctor rather than the patient (worries about promotion, getting sued, etc...) and this can influence testing behaviour
- medical systems can be distorted by the charging regimes for tests to either order too many tests or to order non-optimal tests (doctors making money by signing test forms...)
- patients can forego tests because of the cost, which can impact the patient's perception as well as possibly be a lack in the medical knowledge relating to that patient

The patient's mental state and expectations can have a significant impact on medical outcomes and even causation. Setting aside discredited notions of 'positive thinking', this means:

- Patients have expectations about knowledge that will be gained from tests
- Patients have reactions to the actual knowledge gained, or their perception of the knowledge gained
- Both mental state and expectations can be greatly affected by mere fact medical testing is taking place

Therefore:

> *The fact of testing has potential side affects unrelated to the nature of the test*

(In the foregoing, if it makes you more comfortable, 'testing' can be taken quite broadly, including things such as lifestyle interviews. It's all medical data and the same thinking analysis applies).

The following two statements are self-evident, and somewhat contradictory:

- Many medical conditions can be better treated, or treated with more confidence, if more is known about their history in as much detail as possible: when were the first signs visible (e.g. change in white cell count); did these signs come and go; what was the medical state when symptoms first noticed; etc.
- Regardless of grey areas about when testing should start in the case of queries, doubts or medical symptoms, **regular, broad-spectrum testing is not recommended for healthy individuals with normal risk profiles**. Even though this is the only way to have better medical history.

Important Statements About Errors

- All testing has an error rate.
- Not all testing is equal: a large pathology lab differs from a small corner surgery, and tissue takes time to transport, etc.
- Tests can have **four** possible outcomes: positive, negative, inconclusive (no safe conclusion can be drawn), and invalid (e.g. problem with data)
- The false negatives and false positives in the previous point are common, and are often guarded against
- 'inconclusive' and 'invalid' can also be false. These **tend to be overlooked** in error statistics (presumably because it is more difficult to measure their error rate, but it demonstrably exists).
- All treatment has an error rate.
- Some of the easiest treatment error rates to detect are very high (e.g. drug dosages, amputations) and there is evidence to suggest treatment error rates that are not so easy to detect are also high.
- There seems to be a kind of universal blind spot about error rates of all kinds. Humans are not good at seeing this intuitively.

Statements on the State of Medicine

These statements are readily supportable:

- Medicine of all kinds and at all levels is **beset by complexity**. Inherent complexity means our total knowledge is a small proportion of the amount to be known, and the positive feedback/network effects associated with growth of knowledge often mean the complexity becomes greater (e.g. Epigenetics.) There is also contextual complexity, to do with the impact of government, ethical and financial factors.
- To demonstrate how quickly complexity builds, **consider multi-morbidity**. Even some of the best-understood and most treatable diseases are not at all well-understood in the context of multi-morbidity, and beyond the limits of evidence-based medical data. Multi morbidity is increasingly common, and yet we don't have a good understanding of how treatments should cope with it. Think of how many elderly patients have drugs for multiple conditions, and think of the number of combinations, and that trials involving drugs in combination are almost non-existent.
- Both the environmental and inherent nature of medicine is **changing rapidly**. The following is a sample selection of things that are commonly thought to differ between successive human generations in modern society: microflora, genetic diversity, background levels of artificial chemicals (body burden), and hormone patterns. Even with just these factors there is great complexity, and if these factors are all changing by generation, the complexity is vastly increased again. Play with permutations and look at some indicative numbers!!!

- Evidence-based medicine is often helpful, but is still very incomplete. It is also regarded as the best we currently have.
- Evidence-based medicine is very difficult to put into practice because of human factors in the medical profession worldwide, even at the level of the simplest routine tasks (classic example, intravenous line cleaning checklists, which when applied reduce an entire class of hospital-caused infections to close to zero but which are notoriously difficult to enforce. Or even getting doctors to wash their hands).
- Empirical data on many variables for large sample sizes is rare (even with just one sampling for each individual in the population)
- Empirical data on many variables **over time** for an individual medical case is rare
- Multi-variable empirical data collected over a sufficient time, when its collection has not skewed outcomes, and when properly interpreted, will always improve medical outcomes

No wonder then that longitudinal studies are regarded as critically urgent by government and also medical companies of all kinds. There are few of them relative to the number of areas of critical medical ignorance, they are regarded as expensive, and worst of all they require long-term commitment by political and medical entities geared to short-term decision cycles. In the UK, Scotland has some of the best long-term data available but the inputs are far from the quality proposed in this document.

Statements Relating to Medical Ignorance

It can be helpful to think about medical ignorance rather than medical knowledge, although they are dealing with the same subject. The ignorance is so much vaster than the knowledge, yet attention is invariably focussed on the tiny amount of knowledge we have.

The following statements can be supported by any medical scientists::

- It is very expensive to reduce our medical ignorance, and frequently the expense factors have to do with personal, social and regulatory issues rather than medical science.
- Medical ignorance is best addressed by considering data about many people gathered over a long period of time.

The following statements seem correct intuitively, but need to be verified by more experts:

- Medical ignorance decreases as the number of valid data collection regimes increases, provided sample sets are large and collected over a long period of time .
- Assuming sound design, the value of a data collection increases with the time it has been running. In other words, the most valuable studies are likely those that have not yet finished.

First Problem Statement

Here is the statement of the first of two problems addressed by this proposal:

> When an individual has a disease or health anomaly we want to notice early and treat with maximum intelligence *however* there are many issues connected with early detection

Dilemmas:

- ethical dilemma - we must choose between treating while lacking good knowledge, and delaying treatment until we have good knowledge, with very little middle ground. Each choice can lead to bad outcomes, and they are mutually preclusive.
- medical dilemma - acting prematurely on knowledge about the patient can lead to: under or over-treatment; uncertainty (ie we know there is a very high error margin); entirely wrong results (eg false negative by misinterpreting tests, or wrong limb); and false certainty (ie we don't know that there is a very high error margin.)
- financial dilemma - inefficiency is expensive. A healthcare system that over or under-tests is inefficient, as is one which generates extra work due to the fallout from errors and uncertainty or false certainty.

Causality paradox:

A patient presents with a previously unreported problem, and a doctor decides it should be looked at closely. At that instant, the best medical outcome will arise if a long and very detailed, multidimensional history of the patient is already available.

However, such a history cannot exist within the bounds of today's medical framework, because, in order to gather it:

- we would never get to that instant of decision with little prior background. Given partial previous information we would have been forced to consider alternatives long before
- the process of considering alternatives due to increased (but partial) information frequently leads to interventions being made even though more information could mean no intervention would ever be made
- we may never get to a position of good information because ethically once we've started a series of tests we need to intervene once evidence gets to a certain point

That's the problem in a nutshell - how can we ensure appropriate detailed historical records are available to treat a patient after diagnosis, knowing that if we attempt to make these records beforehand the patient may be worse off.

We can be pretty sure about the *worse off* statement, because of the foregoing statements concerning error rates in testing and treatment, combined with the statements on current medical ethics. Over a large number of cases, ethics will require interventions and some interventions will be either faulty or unnecessary. **Hence the status quo: regular broad-spectrum testing is not recommended so these issues never arise.** What we don't know can hurt us, and what we do know can too.

Second Problem Statement

This is the second, larger-scale problem addressed by this proposal:

> Medical science is ignorant in many fields because good empirical evidence about populations either has not been collected or there are ethical and practical barriers to doing so

Ethical, Medical and Financial Dilemmas:

- *ethical dilemma* - quality empirical evidence is all about hands-off observation, however, observing a sick patient closely will often yield information that could help the patient.
- *medical dilemma* - medical action is often required even when the knowledge behind the action is based on incomplete or non-existent empirical data. This is when doctors have to make the best judgement they can, often after careful consultation with collegues but still essentially a guess. Part of the skill of being a doctor is handling two areas of poor information at once: that of an individual's history and that of the science bearing on the individual case.
- *financial dilemma* - good empirical datasets are very expensive to gather, and take a long time. Expensive + Slow is not what medical companies or governments want to hear.

Medical hubris is not considered anywhere in this document, but if it was this it would belong here.

Solution to Both Problems

The solution is to construct a time-travelling medical testing and diagnostic service. As stated above, the effect is that regular, broad-spectrum testing is done but the patient is strictly barred from seeing any results or even knowing what tests were done.

> The key point is the direction of information flow. Everything flows into the testing centre. This covers: direct testing of the individual; a running record of what (if any) the medical care system is doing with the patient; and aggregating the above information across many patients and drawing conclusions about this individual. A reverse flow of information to the patient other than an after-the-established-fact release of information would be harmful to the individual and to the wider goals. It destroys the entire premise of the Medical Snapshot Service due to causality.

See also the two Information Flow diagrams at the beginning of this document.

Financial motivation: state and commercial interests wish to decrease medical ignorance by large-scale high-quality data collection, but doing so effectively costs far more than can currently be borne and so many other directions are pursued. An alternative re-statement of this: funding for decreasing medical ignorance is often narrowly and inefficiently aimed, and frequently consideration is only given to people alive now, or likely soon to be alive. Ideally a way could be found to efficiently address medical ignorance while also immediately contributing to those adults who pay for this work.

Participant motivation: individuals wish to participate in a form of medical information insurance lottery so that, should they discover they suffer from a medical condition, there is a reasonable chance a full diagnostic history relating to this problem will be available to their medical carers. The individual accepts there is no right granted for any kind of information or meta-information relating to their own medical information.

Individuals are paid to undergo Medical Snapshot tests. These will be administered in a very low-key way, usually self-administered and rarely if ever required to attend a testing centre.

Here's how it works:

1. Individuals are contracted by a Medical Snapshot Service to undergo medical snapshots during an agreed period of years (or maybe the rest of their life) subject to some special rules. The Medical Snapshot Service never provides any medical services of any sort.
2. Life for the subject proceeds as it normally would - if someone normally goes for a medical checkup then that's what they do, if they normally avoid doctors then that's fine too. They use whatever mix of healthcare they choose to.
3. At a point where the individual's doctor knows there is a medical problem, or can demonstrate a high probability of a problem, the individual's doctor may apply to the Medical Snapshot Service for a medical replay report. The doctor must submit the total medical knowledge relating to the individual, highlighting the knowledge which led to the report request.
4. Entirely at the option of the Medical Snapshot Service, a report can be released detailing everything the Centre considers relevant and that the Service wishes to divulge. The Service

may choose not to release any information, regardless of what information it has. There are good reasons why the Service *may* choose to withhold test results, mostly related to upholding its core mission. This is one of the main reasons why the individual must be offered money for submitting to the tests, because the tests can then be viewed as a finished transaction. The Service owes nothing to the individual, but since it is not a for-profit business aimed at improving human well-being the Service it will do everything it can consistent with its charter. In addition, the Service ***must*** withhold results that are not related to the request submitted by the individual's doctor.

5. The design of the Service makes it possible for the Service to ignore requests from a court, or an individual's estate/family, or a health insurance company etc. The design involves, at the very least, information taken at the point of testing being unreadable until it arrives in a country that does not have a very compatible legal system to the country in which the tests are done. A lot of work has been done on designs like this, so it is not something that needs to be discussed any more at this stage.

So in summary here are the rules relating to the medical snapshots:

- No access to any results is permitted by the individual or any legal or medical system.
- No specific knowledge of the nature of these snapshots is known. Body fluid samples, advanced scanning technologies, perhaps a treadmill or gait analysis, maybe a lifestyle form or a psychological analysis - the Snapshot centre will decide which collection of tests to administer to a subject on each visit.
- Nobody anywhere in the legal or medical system is permitted access to these records except as part of anonymised studies.
- There is no guarantee of service, or non-service, or even that tests are taken at all on any particular visit.

This is the outline of an *experimental but immediately practical* healthcare solution. Related areas for developing a theoretical model around these ideas include epistemology and logical positivism besides the usual medical, legal and informatics fields. A model is important, but my hope is that there is enough practical merit and financial incentive to start to look at these ideas as they stand.

Clearly, normal medical/ethical/legal rules and risks do not apply to this process, instead, there are some very special but quite simple protocols that need to be developed and approved.

Potential Funding Sources

I left this as a mere footnote, because it is pointless to discuss funding until the basic premise has been validated at least to a very basic level. Apart from traditional fundraising (and medical funds are awash with money at the moment), there is government involvement due to the immense sums at stake over the coming decades; pharmaceutical industry involvement due to the reduction in cost and risk for new treatments; and wealthy medically-focussed funds such as Robert Bosch Stiftung, Wellcome Trust, Rockerfeller Foundation and the Howard Hughes Medical Institute. There are several very well-funded ageing and longevity institutes that may find this a useful tool to measure actual and potential effects of various factors.

End of Proposal

Evidence of Thought

The rest of this document is additional information to demonstrate that a good level of thinking has been done. All of the following will be relevant to external review. None of it should be relevant to developing initial proposal and financial models.

In some respects, this is a moonshot: it has the potential to change the world, and the spinoffs are potentially very large.

But in other respects it is a very cheap thing to try out: even within just one hospital it would be possible to create chinese walls between people who are all authorised to view all data, and to simulate the snapshot system without any breach of existing regulations or convention.

And the data that would be generated is something desperately wanted by organisations with a capacity to pay.

Extra: Assumptions for the Snapshot Service

The following assumptions are built in to the design of the Snapshot Service.

- The goal of the Snapshot Service is to reduce medical ignorance
- Reducing medical ignorance has commercial value.

- There will be no mandatory reporting, something that will be contentious and may in the end need to be addressed by a kind of logical interlock or fuzzing system.So, for example, tuberculosis is infectious and can often be detected long before symptoms are present. The Snapshot Service is under no obligation to communicate a positive TB diagnosis. The Service might decide that the best outcome for decreasing medical ignorance is to monitor the patient until symptoms are noticed via the standard medical system. As a bald statement this is a horrifying prospect (imagine being the lab technician involved!) and for some types of illness may even be against the law in some countries, but an appropriate protocol could probably be developed for anything which is potentially pandemic. Given the observer-only protocol, it is also feasible that all parties could undertake to accept short-term harm and even deaths in exchange for much greater human savings later: although disturbing on the face of it, medicine is about balancing risks and benefits. As a balancing comment, TB is an example where some individuals correctly test positive to TB are not infectious. The nature of these false positives is highly valuable information relevant to the health of many people - so perhaps even in this case the greatest value is in remaining silent, with safeguards. Then too, there are simply no empirical studies of the effectiveness of TB mitigation responses (because it would previously have been highly unethical to make them), so measurements of this would be highly instructive. The ethical dilemmas are profound. Another scenario is the rare but proven incidences of individuals with immunity to normally serious diseases, something that can only be detected by accident normally because the immune individuals do not present with symptoms.
- As an example protocol in the TB case, following diagnosis, the Service may choose to release a full history to the TB patient's doctors, indicating that other people could have been infected for up to six months previously. That will help the disease control centre decide where the perimeter of infected people lies - it could also make people very upset because of the prevention that could have been done. That is the premise on which the Service operates.
- There are other very difficult possibilities that arise, for example, when the medical care is clearly making incorrect decisions about a patient, either due to lack of competence or lack of knowledge, sometimes setting up a patient for a Never Event. However, intervening in any *ordinary* sense would completely destroy the premise of the Snapshot Service. Depending on how early an intervention was made, it could even be harmful to the patient if it stimulates overtesting. Therefore, the only option is to remain silent. Again, there could perhaps be some carefully controlled and minimal protocol for suggesting that the medical carers take a second look at a case.
- The Medical Snapshot Service produces data that needs special protection. Since in principle this protection is equally valuable to all government and individuals, it is in the interests of all parties to respect confidentiality. Think of diplomatic bags, perhaps even literally as the

data leaves the country. Snowden issues arise in this analysis.

- No Medical Snapshot Service staff may handle data that may include populations they –are familiar with. This goes well beyond normal medical protocols, which merely guard against accessing data of individualls that are specifically known.

- We assume that there is a way to keep the required absolute barrier between the Snapshot Service's data and any interested party. To be proof against governments' curiosity and their tools (e.g. anti-terror legislation, personal legal threats against Snapshot Service staff or contractors, etc.) and any other party that may wish to either access or subvert the data there will need to be some good solutions in place. This comes down to a well-understood security analysis problem, where potentially compromised collection points provide data for central collation which must not be able to be accessed without authorisation. The system needs to be designed so that the worst that can happen is that results are compromised in just one collection centre.

- We assume the existence therefore of technical and legal mechanisms to make this work. Most of this already exists in one form or another, although its application to medicine would probably be a first. The task is one of multi-disciplinary integration and a technological rather than a technical approach.

Extra: Avoiding Distractions

When considering these ideas it is very easy to get sidetracked down distracting rabbit holes of detail. The following are are well studied in their own right, and don't need to be further considered in this discussion. They are all interesting, but just a distraction here.

Topics that don't need to be considered yet include:

- Ensuring confidentiality of centrally-stored data. There is a field of study that addresses how to store information across legal jurisdictions and using technical means such that it is impractically expensive from many points of view to compromise the data. The results of Snowden are encouraging in the sense that there are classes of security that are now known to work effectively. They are also discouraging from the point of view that we can now be certain the Snapshot data will be under vigorous attack by the UK and other well-funded governments, besides the other potentials.
- Gathering data in a non-invasive manner. Advances in medical diagnostics have produced a generation of devices which are small, have low energy requirements, are capable of encrypting data at source and have low error rates. Where physical samples are required the sample size is dropping all the time.
- Authenticating participants. Self-service diagnosis usually does not require individual authentication. In this case it may well be essential, and there are some robust ways of doing this.
- Not leaking information. Even the fact that an individual has submitted a particular test result is not information that should be available to any external party, nor that certain instruments have been used in a particular period - after all, this could be used to definitively demonstrate where a particular person was at a certain time time and date. This problem is addressed by important and well-studied fields of computer science. An individual's doctor will know there is a Snapshot history because they will have received a request from the individual to submit all records to the Centre as they are generated. This means that a doctor knows she can make a request to the Service even if her patient is too sick to remember it is an option.
- Legal mechanisms to enable violation in a very specific narrow sense what are clearly fundamental rights guaranteed irrevocable by overlapping networks of laws. There are tested mainstream and ethical ways of doing this already.
- Headquarters and structure. There is scope for infinite discussion between legal, commercial, political and informatics experts as to the best way to set up such an organisation. The point to remember is that a solution can be found. Exactly what and how can't even be resolved without consideration of the precise environment at the time, so there's little point in worrying about it now! Alternatively, there are technical means by which there would be no single place or jurisdiction that had all or even an identifiable piece of data.

Extra: Criticisms

There are many! Here are some, in no particular order.

- **Shouldn't be called a Snapshot Service**. Probably right, because although there will not be any continuous measurement or testing (nothing will be implanted or irradiating! :-) the rate of change in a subject will mostly be slow relative to the frequency of testing. Therefore it is effectively continuous, even more so compared to common testing intervals. So let's find another name! 'Continuous Anonymised Testing', maybe. My favourite so far is 'Private Medical Panopticon'.
- **Very few will want to sign up**. First answer: who knows – we need to research it! Second answer: if you consider the number of people already willing to *pay* for this knowledge, that establishes there is a pool of interest. How large that pool is, or how amenable to influence it is, remains to be seen.
- **Human tissue is not data**. Quite so.
- **The legal barriers are too high**. Not necessarily. It is already, clearly, permissible to send all your medical details plus personal samples to a medical lab in Mexico, because this happens a lot (by desperate people responding to advertising for quack cures.) UK law doesn't say anything about what a Mexican lab does with samples willingly sent there nor of the information sent back. A lot of that activity – and Mexican facilities aren't the only offenders – would be illegal in the UK, not to mention unethical everwhere.Between what a Mexican lab may do and what UK law forbits lies a range of options I

  > It is not possible for someone to sign away basic rights, and equally true there are vitally important EU and UK laws covering collection and handling of data.

  Nevertheless this proposal is unprecedented in several ways, and new and more stringent protections would be required than the law can currently provide - while at the same time some legal requirements must be avoided such as mandatory notification or cooperation with certain kinds of police demands.
- **The technical barriers are too high**. No, this is definitely not true. I have avoided going into the technical aspects of this idea because there are so many known-good technical solutions to all the problems and opportunities identified so far. From protecting data from either its originator or governments to ensuring that the alleged subject is in fact the correct subject, to helping and protecting the collators of the data to ensuring consistency and correctness over time - all these things are very well covered. As a technical challenge, this idea is perfect for the medical, legal, security/privacy and other geeks.
- **The ethical barriers are too high**. This may be correct. If a robust ethical framework cannot be developed then the outcomes of this scheme will have no standing. Against this, there are already huge ethical dilemmas in the private medical testing industry. It is time these were addressed!
- **Medical research has already figured out the ethical barriers.** No it hasn't! Especially when involving the world's most vulnerable populations. One of Oxford University's famous AIDS studies in subsaharan Africa is observer-only, with only very modest exceptions. While the researchers do advocate basic precautions, for *decades* these well-funded Western researchers have tested destitute women, observing them engaging in marginal lifestyles that we know can be fundamentally changed with a little practical and advisory help. And yet universities and pharmaceutical companies need the data so millions get poured into watching. From http://www.guardian.co.uk/world/2007/may/27/aids.features

  > *Elizabeth Ngugi is unconvinced by this line of argument [from the male research leader]. 'These women have given the world such a huge body of knowledge, but what has the world done to help them change? The research findings have given us so much, but what have we given back? There is more research money coming all the time - quite*

clearly there is an imbalance.'

Extra: Interesting but not Directly Relevant

Time Patrol

There is some commonality between this idea and many science fiction stories that explore time travel where it comes to the direction of information flow. A common fictional device is to introduce some kind of Time Patrol, an enforcement body whose job is to prevent knowledge of the future contaminating the past for fear of altering the future. The idea here is that consistent causality trumps other ethical considerations, and similarly for the idea of a Medical Snapshot Service. If there is any possibility that Snapshot information is available to an individual before any knowledge of a problem then the entire idea is destroyed. That is why it has to be strictly an observer-only system, and the individual must never think of it as a medical service.

Individual Medicine

There is a link between the way the Snapshot System works and the work being done on individualised medicine, including targeted genetic cures.

Possible Principles

I suspect we can go one step further and formulate three principles behind the Snapshot System:

- Studies that run indefinitely will always be financially more efficient for a medical system.
- The further in the future we aim when designing a study's intended benefits, the more certain the financial rewards.
- There is often low marginal cost to collecting a broader range of better-authenticated data if data is going to be collected anyway. What used to be an expensive test is often now a simple swipe through a portable electronic analysis kit that can tag data from the point of collection.

Taken together, these suggest the possibility of either a market or state-sanctioned national investment in long-running and **broad** studies. Where this happens now it is one or more of: narrow, spotty, accidental.

If these three suggested principles can be verified it would drive some very interesting discussions about resource allocation.

Next-but-One Researchers

The thinking behind the Snapshot Service implies the need for a new kind of medical doctor/researcher, one whose entire interest is the health of the next-but-one generation. This differs from most researchers, who are financially or otherwise committed to helping people in the foreseeable future. Perhaps the first version of this could be in epigenetics, where presumably there is a need to gather information for studies to be done 25 and 50 years from now.

Failure Definitions

I proposed above that the longer a well-designed experiment runs, the more valuable it is. If so, this implies two things:

- ending a longitudinal study is a form of failure
- a study is a failure if another researcher cannot easily take over the running. This is because the best outcomes will otherwise condemn researchers to a career in one single study, because they have to be long-running and nobody else can do the work. This increases the

risk of monoculture errors and/or groupthink.

It is good management practice anyway to make sure protocol and procedures are clear and documented.

Hypotheses

The following hypotheses developed as thought experiments and helped me formulate this idea. They are testable:

- Hypothesis of medical testing 1 - Error rates increase with the number of tests done *during a sufficiently short period of time.*
- Hypothesis of medical testing 2 - Error rates decrease with the number tests done *during a sufficiently long period of time and in the absence of treatment*.

Chances are high that both of these hypothesis have been discussed in specialist texts, and I am just not aware of it. The second summarises an ethical dilemma. An investigation of these two hypotheses could be very worthwhile.