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National Digital Health Strategy -
Have your say

ABERNETHY HEALTHY LIFESTYLE ASSOCIATION (AHLA) was established in 2012 with a primary objective to improve health in our local area by developing opportunities with cross-disciplinary approaches for prevention and control of diseases for which obesity is a contributing factor.

With recognition that causes of disease associated with obesity are complex and can be strongly related to lifestyle, an holistic approach should be inferred.

AHLA is a small group whose members have little or no formal medical training. Because of this, our greatest priority has usually been on preventative activities that self-evidently decrease obesity but may be difficult to accomplish in our area due to its small population and tradition-driven social environment or in all areas due to lack of priority by other stakeholders.

In line with this approach, this submission entreats the Australian Digital Health Agency to prioritise digital implementations that aim for **PREVENTION** of poor health at or above all other priorities. This is because prevention of disease, as well as injury, is quite possibly the surest way of reducing health spending in any degree comparable to the obvious efficiencies promised by an Australian digital health project. Besides being morally superior, prevention will continue to drive cost down if <u>more</u> health and health risk data is analysed by <u>more</u> people using better tools with a view to <u>more</u> non-medical interventions. In particular we suggest the National Digital Health Strategy should :-

1. **Explicitly address public concern for storing HEALTH DATA** in a way that assures the public it is collected and accessed safely, and is of great humane as well as economic benefit;

2. **Develop and implement a SHARED INTERVENTION STATISTICS DATA MODEL** to enable greater and more efficient use of more varied measurement efforts;

3. **Ensure MENTAL HEALTH RISK FACTOR DATA is easily linkable**

4. **Implement INFRASTRUCTURE BUSINESS CASE PRO FORMAS** in recognition of the fact that these intervention measurements may justify and help pay for infrastructure investments that are likely to be effective in reducing the community expense of lifestyle diseases, a growing cost to Australian Taxpayers. These investments may also motivate healthier lifestyles.

5. **Implement INCENTIVES FOR NON-MEDICAL PROGRAM PARTICIPANTS** by

recognising the importance of, and encouraging, non-medical processes in promoting healthy lives that avoid disease cost burdens.

In more detail...

1. Explicitly address public concern about risks concerning HEALTH DATA

The ePIP Software Conformance Overview indicates that the My Health Record system is relying on software suppliers to implement Healthcare Identifiers which it then requires to be available for electronic messaging and for use in the My Health Record system.

We also note that plenty of people are nowadays wearing e-bracelets measuring health data about themselves.

The benefit of allowing personal data to be used by a doctor when visiting a doctor can be discussed with a doctor. However, the benefit of allowing data about one's overall health - that may not be perceived as relating to a doctor's visit - does not yet seem to be being discussed with the general public in any kind of coordinated, informed way. Inertia suggests this kind of data may not become as available to researchers as desired if this remains the case because the benefits of allowing its use may not be realised if the potential is not publicised.

In an environment fraught with privacy and liability concerns, the cost of implementing the infrastructure required so that this data can be used as beneficially as it could be used is probably too high relative to the likely or possible profit of private enterprises. In fact "BigPharma" interests would likely confound the possibilities. With privacy of medicare off the table, a mechanism *outside government* for realising the vast benefits of avoided health cost has not and possibly never can build a realistic business case sufficient to outweigh the costs implementing it.

Where preventable lifestyle disease cost is counted annually in Australia in tens of billions of dollars it is likely the business case only works for a government-led initiative.

Before implementing anything though, the people of Australia need to understand the aims and possibilities of this project. They also need to be able to easily access credible information about it - What is health data? What are the benefits of collecting it? How could it be done? What are the risks? What are the various degrees of solution managing those risks?

There is much concern about privacy and there are many ways to collect information with personal details stripped out. We understand that the important nexuses between security and usability of that data are :-

- In what manner and with what protections people will feel safe about reattaching items of their stripped health data to other pieces of stripped data that pertain to them as an individual? and
- At what times and in what form can those pieces of data be reattached to data that would allow identification of them as an individual?

There are probably lesser cost solutions than having each person carry some device that is

able to access networks and requires a fingerprint and password when giving asynchronous permission to researchers. (For example via a packet containing the set of keys (no identification details) from just the relevant part of the person's encrypted personal master record that contains all the pairs of their personal_keyids for the different schema_ids that the person has consented to participate in during the course of their life). Nonetheless, technology advances have already built these kinds of strong solutions into the controls that protect bank accounts of high wealth individuals and data worth millions of dollars that can be encrypted with private keys on 'the cloud'.

Similarly to the different NBN technology cost scenarios, those lesser solutions would need to be devised and tested with focus groups so they can be essentially described by their biggest risks, biggest benefits and costs for a national campaign.

After an initial social media and television campaign, surveys should ascertain attitudes towards the solution/s. Some kind of two stage cluster sampling of attitudes covering the whole country would be a small cost in the scale of getting it wrong and either having insufficient people opting in or not getting the system going in the first place.

2. Develop and implement a SHARED INTERVENTION STATISTICS DATA MODEL

The potential for growing private contribution to public infrastructure via social impact investment may increase if it becomes economic to successfully map measureable improvements related to health onto particular infrastructure development projects. A standard way of managing and sharing data will reduce the cost of objective measurement needed to justify health prevention investment on the basis of future cost avoidance.

The data model needs to be designed to optimise the cost of implementing measures for acceptable data security against the ongoing cost of maintaining and operating the data repository, as well as for the potential savings in avoided disease as a result of using it successfully.

The usual way of designing an efficient data model is to find commonality of structure and function and use it to minimise space, redundancy and complexity, to make the data as securely accessible as it needs to be to the transactions that are needed to use it and to be as robust, simple and evenly-coordinated with respect to hardware that is only as fast as it needs to be to work acceptably. Higher priority on any of these different aspects comes at the cost of one or more of the other aspects (more cost, more complexity, extra processing, extra space, less security).

When designing a system to be used in ways that haven't even been thought of yet, most analysts design firstly for an idealised model catering specifically for the kinds of information they already know about using a process known as normalisation. They then test it with all the transactions they think will exist to find inadequacies and possible problem 'hotspots'. The basic aim is to fit each individual type of information into standard formats which can be stored and dealt with efficiently but can be understood, interpreted and changed to reflect

the reality of the system it is implementing through actions designed by reference to the schema (meta-data templates).

A seemingly complicated but actually fairly simplistic example of one part of the design is described in Appendix A. Possibly still inadequate, it attempts to show that it is possible to separate measurement data from identifying data but still render the data accessible to other interventions. The extra data and processing designed to allow this is overhead to what would be required if identifying data were allowed to be safely stored with the measurement. There is highly likely to be a spectrum of solutions that would compromise different data security and efficiencies in varying degrees.

It is likely worth the extra expense of assigning different teams to the problem and then exploring the advantages and disadvantages of each solution to arrive at the best one saleable to the Australian people.

3. Ensure MENTAL HEALTH RISK FACTOR DATA is easily linkable

Various work safety organisations already collect incident records that allow them to analyse safety risk factors in workplaces. We assume that because of the great social, political and economic cost of crime and suicide, opportunities to identify risk factors for poor mental health are also being sought.

Safety researchers drill safety incident data to find safety risk factors that they pass on to equipment designers and to workplace managers who act to reduce those risks in their own workplaces. A national digital health data system that allows researchers to link health & lifestyle data with depersonalised incidents (suicides, police reports, convictions) that can be understood as mental health issues may identify interventions that could reduce suicides, domestic violence and drug addiction cases.

4. Implement INFRASTRUCTURE BUSINESS CASE PROFORMAS

Taxpaying Australians are learning about the cost of Obesity to Australian society. It was conservatively measured in 2011-12 by PwC[1] as $8.6billion per annum and is most likely rising (in comparison to $8.4b total expenditure on housing in 2011/12 by all governments in Australia combined[2]). As obesity cost is mostly avoidable, and because of the likely effect that well-designed Active Commuting infrastructure can have on road fatalities[3] and reducing traffic, it is quite possible that provision of Active Commuting infrastructure in the first instance is a more efficient use of capital in the long term than building roads without it.

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[1] "Weighing the cost of obesity: A case for action" PwC October 2015 estimated in 2011-12 based on evidence with $3.8 billion in direct costs and $4.8 billion in indirect costs including co-morbidities associated with obesity such as diabetes, heart disease and cancer.

[2] National Commission of Audit (Table 3.1.1: Commonwealth, States, and Commonwealth payments to the States expenditure, 2011-12 on http://www.ncoa.gov.au/report/appendix-vol-1/3-what-do-govs-do-in-aust-today.html)

[3] In 2012, bicycle riders accounted for around two per cent of all fatalities in NSW, with seven killed and 1,025 injured. These fatalities doubled the following year. Calculations by NRMA (Using 2009 data from The Bureau of Infrastructure, Transport and Regional Economics (BITRE) adjusted to 2011 Quarter 3 prices) estimated the average cost of road crashes for the following categories for NSW for an individual in 2011 dollars as : Fatality: $3,180,598, Serious injury: $316,869 and Injury: $17,511;

Population and disease data is already used to target and plan infrastructure like hospitals. If a sufficient obesity reduction outcome can be detected with sufficient statistical power in a place where a particular lifestyle disease preventing infrastructure investment has already been made, then it makes sense to create templates to justify further investments in similar health infrastructure under similar circumstances in areas where the local population has high incidence of obesity.

Where to find such a measured outcome though?

Investment programs are already being assembled to help reduce state public expenditure on social services. In one of these (with a business case focused on meaningful job creation by Wonnarua Nation Aboriginal Corporation, submitted to NSW Government OSII RFT10007151 on 12 December 2016 as response number 0000142915), an attempt was made to demonstrate that infrastructure can be justified on avoided employment benefits. Even though the prime business case was not of direct consequence to NSW Government budgets there was indirect applicability to the state's social budgets because of the size of the potential benefit to the state government of assessing a null hypothesis on one of the proposed "lesser" interventions. The likely health effects of the investment to be made in that program were pretty much ignored because of the strength of the economic development potential (including avoided employment benefits) in the area. This may not always be the case so the opportunities that were built into that program for developing health outcome data should be considered if that investment program goes ahead.

At this stage AHLA has not seen avoided disease burden used in any health infrastructure investment business case. It is to be expected that statistical power would require more data than anyone would normally try to justify collecting but it is intuitively apparent that it should be attempted. To encourage data to be collected some infrastructure investment business case templates should be released to motivate people wanting that infrastructure. It doesn't particularly matter why people add healthy activity to their lives, just as long as they do do it. One group's aspiration for better, more livable cities can open new possibilities for more Australians to lead healthier lives, as it reduces Australia's future taxation burden.

The usefulness of business case templates applies even more if the same infrastructure can be shown to achieve other important or politically desirable aims. For example :- Are people who are exercising in this way happier and less inclined towards anti-social behaviour (eg crime dropping by 74%[4])? Could the infrastructure increase education and tourism due to higher quality access to cultural sites and nature? Could it reduce need/demand for road redevelopment, maintenance or for other public services? Could it increase biodiversity? These are all possible but similarly to the investment for reducing un/under employment, is often less aligned with private investment incentive than it is with avoiding taxpayer cost in the future.

It is highly likely that the data required to support business cases will be distributed

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[4] Harnik, P & Welle, B. (2011.) From Fitness Zones to the Medical Mile: How Urban Park Systems Can Best Promote Health and Wellness. Washington, D.C.: The Trust for Public Land. and the https://www.bicyclenetwork.com.au/media/vanilla_content/files/Active-cities-report.pdf

throughout private institutions powered by private interests. Nonetheless it is still in the common public interest that the Australian population be as healthy as possible and avoid as much future cost in disease burden as possible. The Federal government as funder of Australia's health system and custodian of the data model driving its evolution should lead development of the preventative health infrastructure business cases.

Social Impact Investment bonds like any investment are based on business cases. However they also allow funding of projects that would otherwise currently require cost transfers that are now allowed in our current system of government. They also encourage private expenditure instead of taxpayer funding.

Experience for managing incentivised investment is growing and given the universal applicability of managing preventative health to save future disease burden, it makes sense to assemble business case templates that could be added to Social Impact Investment programs to encourage communities around Australia to improve federal health budget economics by aspiring towards good health on account of their wish to have cycleways, community swimming pools and the like.

It would also help prioritise collection of preventative data.

5. Implement FURTHER INCENTIVES FOR NON-MEDICAL PROGRAM PARTICIPANTS

In May 2105 AHLA made a submission to Cessnock City Council's Health Strategy process that we named "Health from the Grassroots Up"[5] and subsequently made public on our website. At the time there was a lack of public writing specific to incentivizing delivery of public infrastructure for population preventative health outcomes. In 1998 Australia's first publicised use of incentives through the General Practice Immunisation Incentive (GPII) Scheme gave 'service incentive payments' to doctors for their notifications of completion of age specific immunisation schedules relating to individual patients. The incentives here were being earned by the nation's doctors. We had found one paper written by life insurer and wellness program operator "AIA Vitality" ("The Case for Incentivising Health[6]") discussing methods and behavioural economics as well as issues involved in implementing wellness programs with an appendix of references that would help setting such programs up.

Since that time, the dearth of specific literature seems to have lessened. In October 2015 Oxford University Press released what they say is the first book to apply behavioral economics to public health and health behavior change. It is published as "Behavioral Economics and Public Health" Edited by Christina A. Roberto and Edited by Ichiro Kawachi.

We suspect it will note there are efficiencies in incentivizing (to the general population) expenditure that is already done as a matter of course - albeit with different prioritisation.

For example it should be possible for Councils to link local public development items to health outcomes like Quitting smoking, Reducing alcohol intake or Losing weight. Council is

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[5] https://drive.google.com/drive/folders/0B4uKkOS96UtJV0tHOWQ3eXlwbjg
[6] http://www.aia.com.au/content/dam/au/en/docs/key_moments_content/The_Case_for_Incentivising_Health_Using_behavioural_economics_to_improve_health_and_wellness.pdf

already making plans for : sports facilities, exercise equipment, drinking fountains, electric bbqs and the like. Items like these could be planned as rewards for geographical areas achieving preventative health outcomes over a particular period of time.

Of course the rules would need to be transparent and clear and a very simple objective health monitoring program within the LGA would need to be designed with independent verification. In some special cases (eg cycleway network development) the reality of demand can be checked using infrastructure usage promotions, especially where there are map outcomes (eg The Great Cycle Challenge[7]) if these non-medical promotions are more strongly encouraged with grants.

While incentive rules evolved they could be supplemented with a chance-based fair reward awarding rationale. This would reduce the likelihood of perceptions of bias by the tally end of the system. There are some simple but effective devices (eg achievement of a simple but supervised goal puts a person's area into an independently supervised lottery-draw that would decide on a first out of the hat basis where a certain percentage of the year's infrastructure would be delivered). Over time the reward mechanism would ideally become less chance based.

A health goal monitoring mechanism would be required as a part of implementing this. It might be possible to incentivise local pharmacy proprietors to work with government on implementing this mechanism.

Independent monitoring of individuals' progress is not just a governance need in the linked public development scenario. It is an incentive to change unhealthy behaviours in itself. The internet & telephone-based NSW "Get Healthy" program has been used by one of AHLA's exmembers already successfully, and as such AHLA carries a link to it on its website. It is reportedly, not collecting objective physical measurements. Local monitoring agencies in rural, regional CBDs may increase NSW "Get Healthy" efficacy. As such state health departments may be interested in helping develop it.

At the bottom of the scale AHLA once worked with a local chemist proprietor on a local Diabetes awareness monitoring promotion project involving a web-based referral system. The staff member involved indicated a willingness to explore further possibilities but there has been little encouragement from those with whom the idea was shared so it remains as yet unexplored by us.

It may be possible to pilot a proof of concept in an LGA where the Council can be induced to consider providing simple health infrastructure incentives (eg tickets in a 'local water-bubbler' or 'local bike rack' preventative health lottery) and developing an auditable ticket protocol conforming to applicable privacy/ethical and gaming guidelines.

In summary, a secure data model should include data oriented towards risk and prevention. Systems should include the extra governance processes and encouragements necessary for partners (including non government organisations) to manage data-driven preventative outcomes as well as template incentive implementation processes.

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[7] If they are not being used this way already!

Appendix A - Example Only
Schema for reusing depersonalised personal disease prevention health data
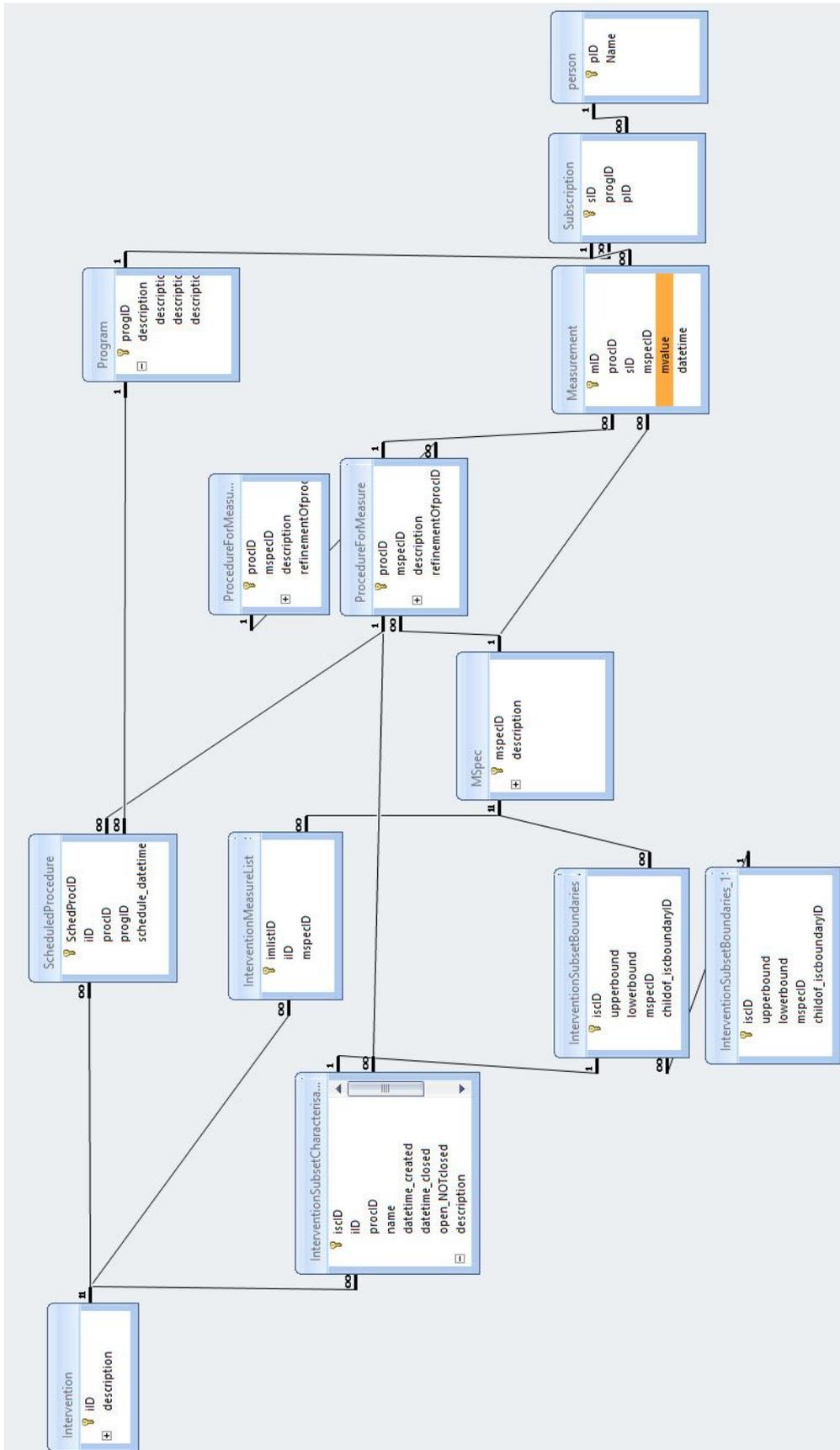
In a prototype scheme - devised only as a thought experiment (with whole dimensions of the design not properly considered due to lack of research experience) - a measurement record of mspecID=234 might have been defined to be a heartbeat measurement.

The structure (or meta-data) of measurement records as supported by the description field in the mspec record would indicate to everyone that the fifth part of the *measurement* record is a number representing beats per minute, the sixth part of the record is a date and time value and the second part of the record is an identifier that gives information about how that measurement wusas captured in the first place.

Because the research institution has a list of the subscribers enlisted in their intervention sample (anonymously, sID is a number only), they are able to check that the intervention participant/subscriber remains within the bounds of eligibility for that particular measurement and therefore configure the data for this particular intervention (or if there is more than one class of participant by virtue of different ranges for that particular measure) to be 'automatically' classified into the correct grouping. It may be that this intervention is only testing people whose rest pulse is between 60bpm and 80bpm and who have brown eyes.

In this scheme a *measurement* would also be able to store static data - as a different mspec (eg for eye colour a limited set of values as detailed in the mspec description could be used) for collection in another part of the same intervention *program* using a different *ProcedureForMeasurement.* Think of it as a survey delivered as per the schedule_datetime field in the relevant *ScheduledProcedure* for this particular *Intervention* and with questions determined by the *ProcedureForMeasure* procID which is indicated in the *ScheduledProcedure* record. (NB There are extra tables and fields not shown in the demo schema that would be required for a 'survey question' mspecID. Without them this particular schema cannot work as a survey with component questions properly. To avoid further complexity in this explanation though these details have been left out. Let's just say for now that here if the measurement being used to classify a measurement record is a type 564 record, then the third part of the record is instead a pointer to a questionnaire record, whereas in all other respects a type 564 measurement record is similar in structure to the type 234 measurement record.)

Using even just the cutdown schema discussed here, the set of all participants who fit these combined criteria (the set of *InterventionSubsetCharacterisation* nodes) at the time the criteria is 'open' can be tracked and scheduled for other procedures dynamically without identification of the individuals. This allows data from these individuals to be applied as existing sample data (with an existing and potentially already sufficient history of measurements) for newer designed interventions in a reasonably efficient way but still anonymous way, only limited by the necessary permission protocols.

To do it, researchers would filter *InterventionSubsetCharacterisation* using the first part (ie the primary key) from the *intervention* record that detailed an "experiment" that sounded like it might have matching qualification data and which dictated that this data be collected (It might be being stored by a health department data registration centre somewhere as a function of the nationally defined process for setting up a registered measured intervention). All applicable measurements would be accessible via the *InterventionMeasureList* (yet another record, owned by the research institute that designed the original intervention) listing the originating intervention measurement's intervention key along with a field containing the measurement type of 234 and a third field containing an *InterventionSubsetCharacterisation* identifier (keyed into a multidimensional matrix of selection criteria (eg males, age 25-60, living in SA3-Lower Hunter, characteristicA on startdate, characteristicB on startdate, characteristicC when collected, characteristic D when collected etc) which the new researcher may even refine without compromising the original structure (*InterventionSubsetBoundaries* are hierarchically arranged. The higher resolution

MSpec would be added again as a child *InterventionSubsetBoundaries* record.). It is via this mechanism that researchers and statisticians could access already collected data and assess it as being statistically powerful for other interventions - so long as the list of *categorisations* of the intervention subset lists was well planned and maintained, and changes to it were continually reflected properly only as new records (ie attached hierarchically to less refined sets if need be).

This categorisation (*InterventionSubsetBoundaries*) list would contain records containing a measurement type, a range description and a pointer back into the list identifying its superset. Each categorisation would include at least four fields eg a record for smoking history categorisation might include:-

- the category key (ie the primary id called iscID, used for referral to this group in sub groups and in other records),
- Access to the categorisation description "smoking history" via mspecID,
- a range "Gave Up for longer than a year on a known date" (or an upper and lower boundary) and
- a pointer to its parent categorisation "Smoked at least once".

A second record related to smoking might the next *category* identified as four fields containing firstly the primary *category* key, secondly the description "smoking history", thirdly the range "Gave up at least once on an unknown date" and finally a pointer to its parent category "Smoked at least once".

This categorisation process and its hierarchy is complex and so the structure supporting it is also likely to be. The easiest way to think of it is to think of a Christmas tree with a piece of string attached to every branch at one end and threaded through its very own hole in a colander at the other end above the Christmas tree. Every time a new branch grows, it is strung into a spare colander hole which is named in some meaningful way so it can be found again by statisticians (but not necessarily with any reference to the originating research that put it there because it may be used for data by more than one intervention).

The measurement record does not need to be stored with any identifying data and yet it can be assessed and possibly included in testing for other interventions along with all the other measured information that was stored for that individual at the same time based on its relationship to an *InterventionSubsetBoundaries* record. Analysis of other measurements taken under other subscriptions can also be used to rule that data eligible for inclusion in alternative interventions. Subject to signup protocls the analyst can use the *Subscription* record (links to a common person without identifying the individual) to access depersonalised data about this individual even if the intervention is not the same one for which the measurement was designed and collected in the first place.