Consultation Paper on the Pricing Framework for Australian Public Hospital Services 2023–24

What changes, if any, to the national pricing model should IHPA consider to account for innovative models of care and services related to virtual care?

AusPIPS is a patient led not for profit charity which provides advocacy and support for patients with Primary Immune Deficiency along with their carers. AusPIPS is highly regarded for its advocacy, especially for its work in the Australian Blood Sector by working with the jurisdictions to help enable SCIg to become a genuinely viable treatment option for patients across Australia for which it has been very successful to date. AusPIPS has come face to face with the numerous problems that inhibit access to SCIg for patients therefore the knowledge it has and shares with the hope that SCIg will be available to all who qualify.

The Australian Society of Clinical Immunology and Allergy (ASCIA) proposes that Immunoglobulin Replacement Therapy (IRT) is the standard of care for patients with antibody deficiency due to a primary immune deficiency (PID) disease or secondary immune deficiency. Both intravenous immunoglobulin (IVIg) – which is administered as an inpatient, day procedure episode - and Subcutaneous Immunoglobulin (SCIg) – which is dispensed to non-admitted patients for administration in their own home – comprise standard of care treatment and should be available for patients in Australia and New Zealand.

Self-administration of immunoglobulins (Ig) by subcutaneous injections (SCIg) is quickly becoming the preferred approach over hospital-based intravenous infusions (IVIg), for a number of reasons, including:

- Providing more steady state immunoglobulin levels in the blood, which is established to have resulted in reduced or even avoidance of hospital admissions and ED presentations, normally associated with fluctuations in patient immunoglobulin levels
- Supporting reductions in valuable nursing and hospital bed resources (where SCIg is available as a non-admitted substitute treatment for IVIg)
- Providing overall improvements in quality of life for patients.

SCIg is a plasma-derived blood product that is funded by the National Blood Authority (NBA) under the National Blood arrangements. However, several other components that are necessary for patients to use SCIg are not funded under federal and/or state/territory funding streams (except in Victoria), including specialist nursing support, infusion pumps and consumables. Immunoglobulin governance arrangements established by the NBA also create substantial work for hospital pharmacy or pathology departments that are not recognised in existing ABF models.

The absence of funding to support the components of the SCIg service model that are necessary for safe administration of the (funded) blood product mean that:

- hospitals are required to provide required staff, space, equipment and consumables from their own resources, and/ or hospitals levy user charges for patients to access equipment and/or consumables or charge dispensing fees. This occurs even though the National Policy for Access to Government Funded Immunoglobulin specifies that patients should access SCIg with no out of pocket costs.

- hospitals are unable to provide dedicated nursing support that is required for patients to be trained in the use of SCIg, or how to support patients adequately on an ongoing basis through 'troubleshooting'.

All of these factors limit the capacity and willingness of hospitals to provide SCIg to patients, in spite of the substantial research evidence that greater usage of SCIg (compared to IVIg) would produce significant enhancements in patient quality of life and savings to the health system.

In addition to these factors, there is a significant discrepancy between inpatient funding of IVIg (~$15,000 per year per patient) and SCIg – for which at best, hospitals (in Vic only) receive around $2,800 per year, per patient. This funding discrepancy creates a perverse incentive for hospitals to maintain patients on a less cost-effective treatment option (IVIg). The incentive for hospitals to keep patients on IVIg then leads to an allocative efficiency issue across the health system because there are thousands of IVIg patients tying up day chairs in hospitals that could instead be treated at home on SCIg. These chairs could instead be used for chemotherapy (and other) patients where home-based treatment is not an option."

AusPIPS believes that IHPA needs to account for changes to the delivery of immunoglobulin therapy to reflect dedicated funding for SCIg in its non-admitted classification, costing and pricing models. IVIg was the norm in Australia for many years but SCIg is now being taken up around the country as a result of policy change by the NBA's Jurisdictional Blood Committee in March 2013 and along with the core role of advocacy by AusPIPS who is now highly regarded in the Australia Blood Sector for its work. Australian governments and health departments are generally supportive when presented with the facts including dramatic improvement in quality of life for patients (a number of which have been responding so well that they are now able to go back to full time work vs. being dependent on welfare) and savings into the millions of dollars per annum. However, hospitals often aren't supportive of providing SCIg because they lose funding (compared to IVIg) and therefore perversely choose to actively block access to patients. Note the examples in point form below.

Highlighting the problems with SCIg access – feedback from the AusPIPS' patient group suggests that:

- Hospitals in Queensland have lied to patients about the availability of SCIg – saying it's not available for adults while providing it for transitioning young adult patients coming from the paediatric system due to a lack of resourcing – no funding for consumables, no staff allocation and no space allocated for storage etc.
- Other hospitals will only offer SCIg for specific conditions – not allowing other patients who also qualify for SCIg to access it in New South Wales and other jurisdictions. Other patient cohorts ask if they can have access to SCIg at hospitals with programs up and running but are told its not available – our belief is due to not having the resourcing including funding because this has resolved such issues in other jurisdictions.

- Some paediatric hospitals have refused to transition young adults into the adult system so they can stay on SCIg - clogging up their hospital in Victoria because there wasn't at that point in time SCIg available in the adult system, which was due again to resourcing – once AusPIPS secured funding for SCIg from the Victorian Govt – such issues were resolved.
- Hospitals have transitioned young adults into the adult system off SCIg onto IVIg telling them it's better for them in Western Australia – SCIg has been until AusPIPS started to work with the state government in general only available to children due to a lack of resourcing.
- Others have bluntly and perversely said they will not offer SCIg to patients who are eligible because they don't get funding and funding is more important for the hospital in Victoria.
- Other hospitals have taken funding notionally allocated to SCIg and, because its not tied to delivery of SCIg, they redirect funds to treat other patient cohorts and then expect staff to simply stretch their time, which limits access as well in Victoria with several major health groups doing this even though they are as well funded as other Victorian hospitals using the funds for SCIg for SCIg.
- A Hospital in the NT still have departments bickering over which department will run the SCIg program several years into trying to get a SCIg program organised – our belief is that an allocated funding stream and if need be, our involvement such as we have worked with the other jurisdictions to resolve problems surrounding access.

AusPIPS proposes that SCIg should be considered as an innovative model of care (see p.30) that has extensive, documented evidence of improving quality of life and where there is also substantial evidence of it being a more cost-effective substitute for IVIg provided in-hospital.

Additional supportive evidence of costings:

The Public Summary Document released after the MSAC Review of PID reported healthcare costs for delivery of IVIg on top of the cost of hospital admission at $5,202 per patient per year, and for delivery of SCIg at $1,404.20 per patient per year
http://www.msac.gov.au/internet/msac/publishing.nsf/Content/1592-public

Additional supportive evidence of improved patient quality of life:

Quality of life assessment in patients who receive SCIg and IVIg
https://adc.bmj.com/content/104/Suppl_3/A306.2?fbclid=IwAR0oUJZrSw7XP0wTRO0D2OK9AcyE_NmCRCg2XCxKw3swwV2jGQMlPvuoNeE

Prognostic factors for health-related quality of life in adults and children with primary antibody deficiencies receiving SCIg home therapy
https://www.sciencedirect.com/science/article/abs/pii/S1521661607012545?fbclid=IwAR3qWLt8XLkXbKzVAZ43AjdvOq_i-ei7KtICcjdyENsYGGbr9Fb8X9Fx3ak