

# NSW Long Term Follow-up ASTRO Pilot Module

## ALLOGENEIC BMT SURVIVORS

In NSW there are over 1600 survivors of Allogeneic BMT. With improvements in donor selection, conditioning therapies and supportive care 35-80% of Allogeneic BMT recipients can now be expected to become long-term survivors and be cured of their underlying disease<sup>1-3</sup>.

The Long Term Follow-up working group (LTFU-WG) of Agency for Clinical Innovation BMT Network is made up of representatives from each of the allogeneic transplant centres in NSW, the Australasian Bone Marrow Transplant Recipient Registry (ABMTRR) and relevant referring autologous centres and transplant recipients. The group published Clinical Guidelines for BMT LTFU<sup>4</sup> in 2016 drawing upon published international guidelines for post-transplant follow-up and Sydney Post-BMT Survey<sup>5</sup>. The guidelines recommended a number of screening criteria over 13 body systems (clinical domains) frequently affected by conditioning and transplantation. There is currently, however, no standardised multi-centre system for capturing the data for these screening criteria in Australia.

### Aim

The project aimed to explore the expansion of Australasian Stem cell Transplant Registry Online (ASTRO) to more comprehensively capture post-BMT outcomes so that it could:

- Facilitate post-BMT care and compliance with NSW Guidelines for BMT LTFU including recommendations for screening and health promotion
- Optimise reporting of post-BMT outcomes
- Enable audit and research in post-BMT care and the experience of survival post-BMT, and
- Inform evidence based clinical improvement at a local and state level

### Method

The project was performed over 4 phases

**Phase 1:** Design and construction of the BMT LTFU module in ASTRO:

- Establishment of the BMT LTFU dataset according to clinical domains (Table 1) to align with Clinical Guidelines
- Programming of the BMT LTFU module by ABMTRR
- Design of the BMT LTFU module data report functionality
- Preliminary testing of the BMT LTFU module

**Phase 2:** Pilot testing for content validity and proof of concept – adult data

**Phase 3:** Modification of the BMT LTFU module for paediatric population

**Phase 4:** Testing of the BMT LTFU module in an adult clinical setting

**Table 1 – Clinical Domains**

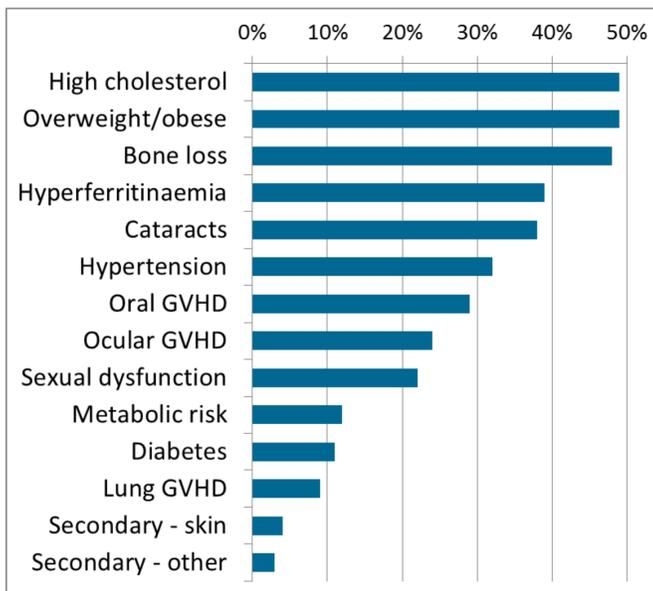
- |  |                |
|--|----------------|
| • Bone                                   | • Liver        |
| • Cardiac                                | • Pulmonary    |
| • Dental                                 | • Renal        |
| • Ocular                                 | • Psychosocial |
| • Secondary cancer                       | • Endocrine    |
| • Genital complications/ Sexual function |                |
| • Vaccine-preventable disease            |                |
| • Fertility and reproduction             |                |

### Results

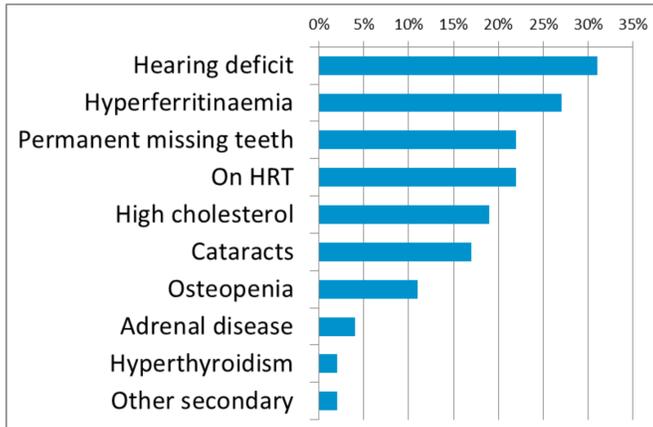
A total of 56 adult (134 appointments) and 39 paediatrics patients (55 appointments) were entered. Phase 2 and 3 patients were entered alphabetically. Phase 4 patients were selected based on having 1 year, 2 year or 5 year data.

Entry time was a minimum of 15 mins but was dependent on record availability. Data was obtained from medical records and at one adult centre the LTFU database.

**Fig 1: Health issues identified - adults**



**Fig 2: Health issues identified - paediatrics**



### References

1. Khouri IF, McLaughlin P, Saliba RM *et al*. Eight-year experience with allogeneic stem cell transplantation for relapsed follicular lymphoma after nonmyeloablative conditioning with fludarabine, cyclophosphamide, and rituximab. *Blood* 2008; 111 (12): 5530-5536
2. Inamoto Y, Lee SJ. Late effects of blood and marrow transplantation. *Haematologica* 2017; 102 (4): 614-625
3. Mohty B, Mohty M. Long-term complications and side effects after allogeneic hematopoietic stem cell transplantation: an update. *Blood Cancer Journal* 2011; 1 (4): e16
4. Kerridge I, Shaw P, Gough J *et al*. *Blood and Marrow Transplant Long Term Follow-up Clinical Guidelines*. Agency for Clinical Innovation 2016.
5. Gilroy N, Dyer G, Kerridge I *et al*. *Sydney Post BMT Survey* Agency for Clinical Innovation, 2016.
6. Australian Technical Advisory Group on Immunisation (ATAGI), National Health & Medical Research Council. *The Australian immunisation handbook 10th ed (2017 update)*. In: Canberra: Australian Government Department of Health, 2017, 2008.

### Conclusion

The pilot has provided the 'proof-of-concept' of the module. The data fields will be refined following the recommendations and incorporated into the routine ASTRO collection to aid functionality and streamline data reporting.

Wider implementation will require detailed planning and resourcing to ensure that staff are adequately trained, that the ASTRO system aligns with local institutional databases and that it facilitates communication with patients and healthcare providers.

### Recommendations

There were 5 key improvements recommended to the module and data collection process:

1. Data prompts modified to record 'since last review'.
2. Adjusting time-points for routine data collection to maximise utility and efficiency
3. Improve baseline data including prior therapy
4. Functionality – multiple platform entry, self determined date reporting structure, data import and export.
5. Data field amendments eg separate clinical domain for skin

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