

Supporting Patients and their Families in a busy Supra Regional Specialist Liver Unit Out Patient Setting

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Introduction

- Established in 1989 the Liver Unit at Birmingham Women's & Children's Hospital has provided supra regional treatment for children with acute and chronic liver disease and those requiring liver +/- intestinal transplantation.
- The Unit appointed a dedicated Clinic Co-ordinator in the early 1990's to facilitate the demanding needs of patients seen pre and post transplant within the busy out-patient setting and to date is the only liver specialist unit offering this service in the UK.
- RCPCH and BSPGHAN published Quality Standards (QS) for PGHAN in January 2017 that apply to children receiving GHAN in secondary and tertiary care settings across the UK.
- The Clinic Co-ordinator is the first point of contact in clinic offering different levels of support and information to patients and families reducing anxiety at their visits to a specialist unit.

Aim

- Review out patient clinic co-ordinator service offered to families and patients at BWCH Liver Unit.
- To determine whether our service meets the criteria set out in The Future Vision for PGHAN in the QS.



Method

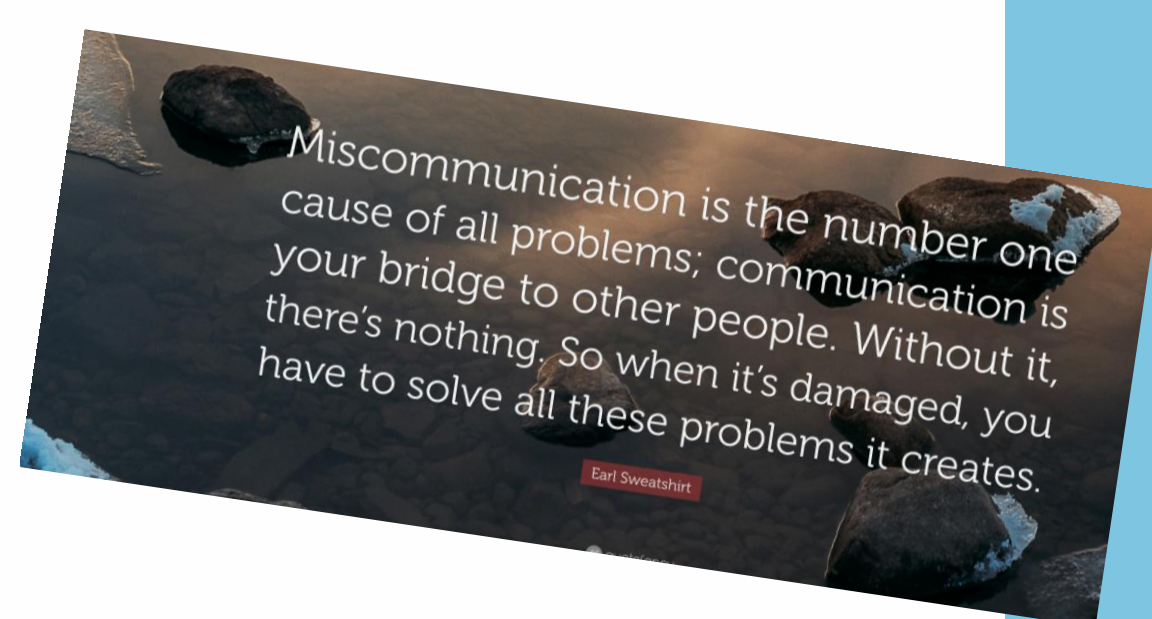
- To compare BWCH Live Unit standards against QS for PGHAN.



Results

Areas identified that meet the QS:

- Clinic Co-ordinator has appropriate knowledge and skills to provide support in an out-patient setting.
- Clinics run in a co-ordinated fashion to reduce anxiety, stress and possible miscommunication.



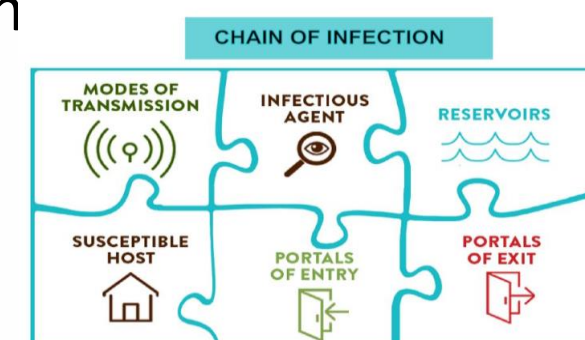
- Communicate with patients and their families who require specialised drugs:

| | | |
|--------------|--------------|---------------|
| Tacrolimus | Sirolimus | Ciclosporin |
| Prednisolone | Azathioprine | Mycophenolate |

- Importance of adherence to treatment in order to obtain accurate results.

Results (cont'd)

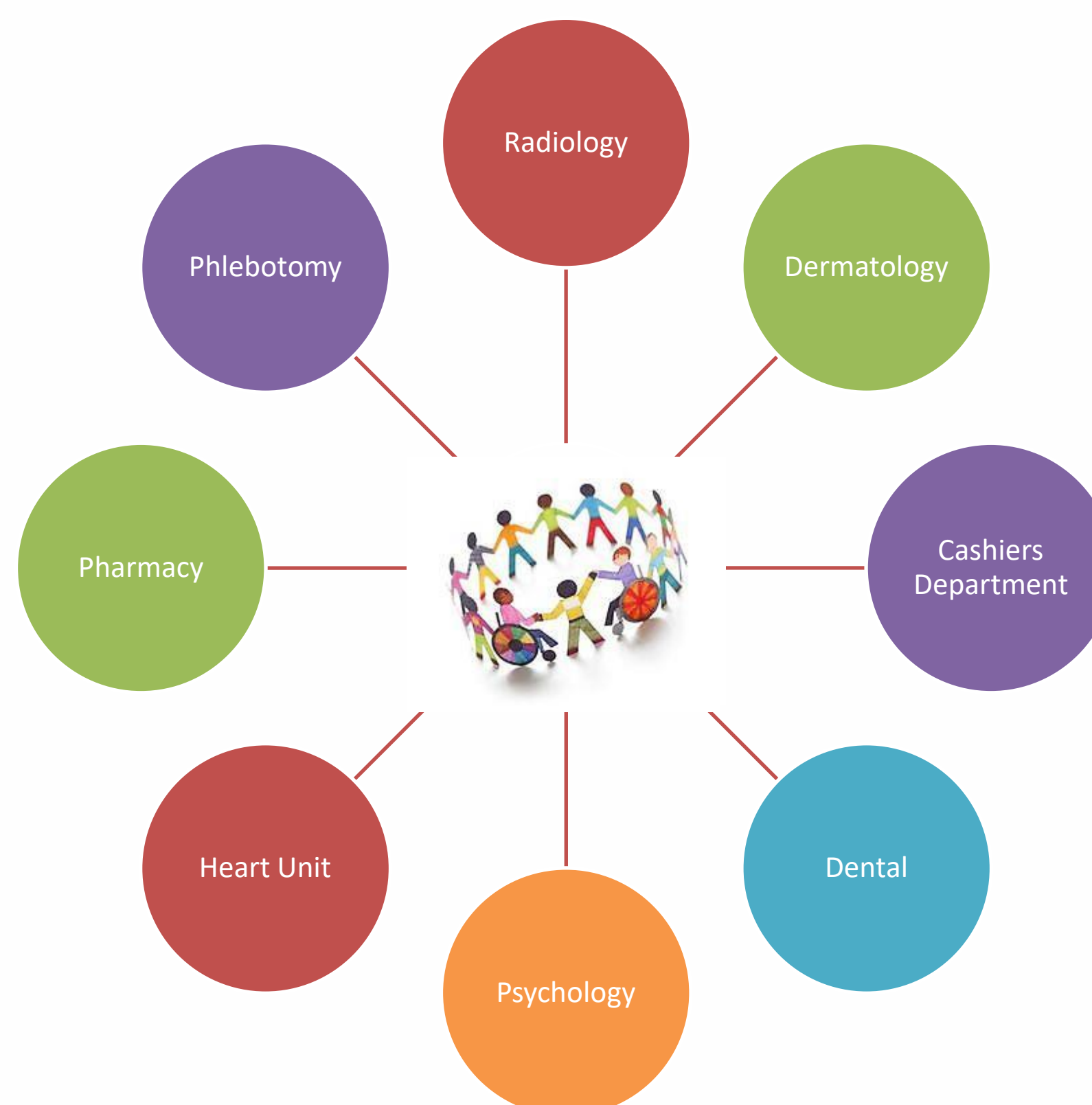
- Inform MDT of patients who are infection risk ensuring appropriate precautions and Trust Policies and Procedures are adhered to within "CHAIN OF INFECTION"



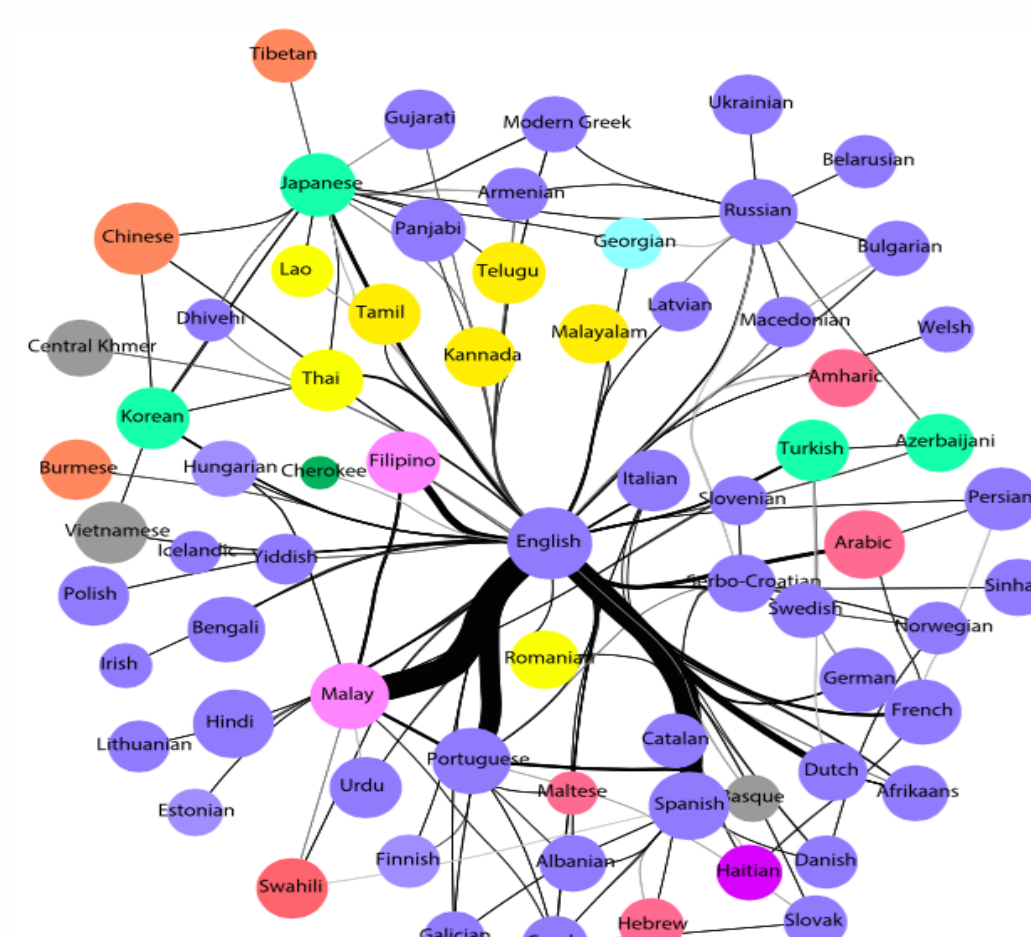
- Communicate regarding those families who require extra support/information regarding their medical condition:

Play Specialist Support for blood taking
Family Support Worker for DLA, housing

- Signposting to other departments/specialities



- Language barriers can contribute to health inequalities and exacerbate underlying conditions due to poor communication between patient, parents and medical teams.
- Non English patients are supported with an interpreter to ensure accurate translation is provided from an independent source.



- Signposting to Patient/Parent Support Groups



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Results (cont'd)

- Work in partnership with the transition team to encourage young people 15+ years to see doctors separately before inviting parental support to encourage independence.
- Weekly reviews pre and post clinic with consultants and MDT.
- highlighting issues for upcoming clinics
- raising outstanding issues from previous clinic

| Day | Clinics (PM) | Clinic Review |
|-----------|--------------|---------------|
| Monday | 3 | |
| Tuesday | 3 | 1400 - 1500 |
| Wednesday | 2 | 0800 - 0930 |
| Thursday | 3 - 4 | 0900 - 1030 |

- Barriers to meeting the QS highlighted are:
Out patient room availability
Dedicated Staff to support clinics
Communication between MDT
Time constraints due to increased clinic activity

Summary

- The Clinic Co-ordinator in the Liver Unit outpatient setting delivers a unique service to provide continuity of care, working in partnership with the MDT, to provide a coherent approach within the out-patient setting currently matching some of the Future Vision for QS.

Possible Future Developments

- Provision of telehealth service for patients and families to enable regular monitoring of patients who have long term health needs or due to geographical issues. Benefit provide patients and families assessment without the associated cost of time and travel are considerable. Potential reduction in DNA rates within out patient setting.
- Obtain feedback from parents and young people to help shape the service going forward.
- Development of Standard Procedures to reduce variation in care and pathways.



- Communication between the Clinic Co-ordinator and MDT is essential to ensure patient journey is consistent and QS are met.
- Ensuring families receive high standards of care within the out-patient setting is fundamental to enable the Liver Unit at BWCH to work in partnership to develop trust.

References

¹Quality standards for Paediatric Gastroenterology, Hepatology & Nutrition, RCPCH: January 2017



By your side