**Other, Specify:**

To report or not to report?

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**Why do we need an “Other”?**

Trends in transplant change faster than we can accommodate with forms revisions

Some trends are fast-lived. Many patients may receive a new drug within a short period of time, but no one receives it ever again.

Some things are just very rare

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**How do we use the specify fields?**

**Forms Revision**
- Specify fields reviewed to see if there new options

**Data Analysis**
- Not routinely used
- May review field, but can only catch *exact text*
- No abbreviations, typos, misspellings, alternative names
- Exception: TCSA fields reviewed, cases lacking information are coded as not significant rather than querying center
What doesn’t belong in ‘other’?

Notes about form data
• Use Log of Appended Documents (Form 2800)
Lengthy text pasted from other applications
Things reported elsewhere on forms
• Symptoms of disease
Anything over 100 characters (includes spaces)
Obscure or institutional abbreviations
Text should be in English

Most Used Specify Fields

Some fields rarely, if ever, used
Most Common are
• Coexisting/Comorbid Conditions
• Conditioning Regimen Drugs
• Graft vs Host Disease Drugs

Comorbid Conditions

From the Baseline (Form 2000) manual:
• ...serious pre-existing conditions that may have an effect on the outcome of the HSCT. The term “clinically significant” refers to conditions that are being treated at the time of pre-HSCT evaluation, or may cause complications post-HSCT.
• Conditions listed in the recipient’s medical history that have been resolved, and/or that would not pose a concern during or after the HSCT should not be reported (e.g., seasonal allergies, osteoarthritis).
Used in TCSA to account for differences in survival rates for sicker patients
Clinical Significance, Con’t.

Some conditions may be relevant for some patients and not others, depending on the primary disease
• Amyloidosis
  • Not reported for myeloma patients
  • Reported for non myeloma patients
• Mixed connective tissue disease for auto immune patients

Some conditions not clinically significant; if severe enough to cause other problems, report those problems.
• Rheumatic fever can cause heart valve problems

Clinical Significance, Con’t.

Comorbidity is not the same as past medical history.
Specific lab values not usually relevant or reportable
• Ejection Fraction >50%
• ‘Obesity’ is not enough info to determine significance.
  • If significant, should be reported under other, other – indicate BMI
• Generic descriptions are not enough info,
  • ‘elevated liver function tests’ - Report ‘Liver disease’

Reporting on CIBMTR Forms - 2400

Form 2400 (Pre-TED) collects data to compute Sorror score
• Very rigidly defined, see publication
  • http://www.cibmtr.org/Meetings/Materials/CRPDMC/Pages/feb2007sorror.aspx
• Includes Pediatric patients
• Other is appropriate in some cases, but be thoughtful
  • For hypertension that is being treated
  • If something is on the 2000 and not in Sorror, then include in Specify
Reporting on CIBMTR Forms – 2000

Form 2000 (Baseline) collects in more detail
- CRF track only
- Specify fields should be used sparingly
- Scored as Yes/No for TCSA

Questions to ask

Is the comorbidity associated with the primary disease?
Is the patient receiving any medical intervention for the condition?
When in doubt, ask CIBMTR!

Quiz – Liver Lab Values Form 2000

a. Other, specify: “ALT > ULN to 2.5 ULN”
b. Other, specify: “AST = 33 units/liter”
c. Other, specify: “Bilirubin above”
d. Yes/No Checkbox ‘Liver Disease’ = Yes

Which of these are correctly reported?
1. A
2. B
3. C
4. D
Quiz – Pulmonary Function

a. Check box for: ‘DLCO < 50%’
b. Other, Specify: “Decreased DLCO”
c. Other, Specify: “DLCO 53%”

Which of these are correctly reported?
1. A
2. B
3. C

What doesn’t belong in Comorbid?

Infections
- There is a separate infection section on 2000.
- Sorror only captures infections being treated
Don’t report procedures, but the disorder that the procedure was performed to treat
- CBA Graft instead of coronary artery disease (which has a checkbox – Q78 on 2000v2)
Don’t report symptoms, report the condition
- Splenomegaly versus Severe Aplastic Anemia
  - Probably goes on disease form anyway

What doesn’t belong, con’t.

Don’t report suspected conditions, only those confirmed.
Be as specific as possible regarding the actual condition
- ‘Palsy’ does not tell us what kind of palsy and is not useful. Better to specify ‘cerebral palsy’
Things not related to transplant
- Broken bones, vasectomy, dental health, tubal ligation, venereal warts, allergies, osteoarthritis
Quiz – Splenectomy

If the patient had a splenectomy to treat their primary disease, where should this be reported?

1. Not reported
2. Disease-specific form
3. Other endocrine, specify
4. Other GI, specify

Quiz - Hysterectomy

If a patient received a hysterectomy for fibroids, what should be reported in the specify field?

1. Hysterectomy
2. Fibroids
3. Not significant enough to report

Quiz – Hysterectomy Part 2

If a patient received the same procedure (hysterectomy) for endometrial cancer, does that get reported?

• Yes, ‘as hysterectomy’ in genitourinary, other
• Yes, as ‘hysterectomy’ in other, other
• Yes, Check ‘genitourinary cancer’ in history of malignancy question
• No, not reported
Relevance of Timing

Remember: “being treated at the time of pre-HSCT evaluation, or may cause complications post-HSCT”

Date of condition is generally not relevant unless timing specifically addressed on form.
  - Some field ask for date (some drugs, malignancy)
  - If patient has a history of illness, probably not relevant
    - ‘Hepatitis A 1975’
    - ‘H/O ANIETY; DEPRESSION ’
    - ‘Hx of seizure;’
    - For exceptions, see Manual

Quiz – History of

Patient had Hepatitis A 10 years ago. Where should this be reported?
  - TED (Sorror)
  - 2000
  - Disease Form
  - Not reported

Reporting Drugs to CIBMTR

Drug lists are very common on CIBMTR Forms

Drugs are listed alphabetically by generic names
  - Some are categorized (intrathecal chemotherapy, monoclonal antibodies)
  - When using specify field, use generic names

Sometimes timing is relevant
  - ATG, ALS, ALG, ATS If given prior to day 0, reported as prep; if given after day 0 its GVHD (for TED, captured on 2400, not 2450)
**Indication for Therapy**

Pay attention to indication  
Be mindful of things that are commonly given for differing intents  
- Corticosteroids may be used as anti-emetic, or may be given as prep  
Do not report same drug under multiple sections unless given for multiple indications. It should only be reported under the appropriate intent  
- ATG given before and after day 0  
If a blinded study, report under other blinded, not under checkbox

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**Conditioning Drugs – CRF Reporting**

When specifics regarding dosing are needed, the CRF data are used  
TED and CRF data should match when possible  
Drugs for disease therapy are reported on disease form.  
In the rare cases where more than one drug needs to be reported in specify field,  
- Use generic names  
- Provide the prescription records with a 2800  
Drugs for prophylaxis (infection, gvh, organ toxicity) belong on 2100

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**GVHD Drugs**

Prophylactic drugs listed on form are intended to be systemic (IV and Oral)  
- Topical drugs should never be reported under prophylaxis  
“UvaDex” is given as part of ECP which has a checkbox – don’t report separately  
Product Manipulation intended to mitigate GVHD symptoms should be reported in product sections (Form 2400, 2006)  
Infection prophylaxis should not be reported as GVHD prophylaxis
Quiz – Reporting Drug Names

Which name for the drug should be indicated in the specify field?
- Generic Name
- Brand Name
- Local terminology
- All of the above

Quiz – Timing and Indication

If ATG was given as 3 doses pre-HCT, and given 3 doses post-HCT, which section is appropriate to report in?

a. Preparative Conditioning Drug
b. GVHD Prophylaxis
c. GVHD Treatment
d. A and B

What are we doing about it?

CIBMTR Clean-up project
- Migrate Legacy Data to new data fields
- Make data more useful to statisticians
- Develop tools to assist in form completion
Planned for 3 Phases and ongoing clean-up
Phase 1 – Review Unique Responses

Thousands of Unique Values reviewed (CRF)
  - GVHD Drugs – 534 unique values
  - Conditioning Drugs – 670 unique values
  - Coexisting Diseases – 16463 unique values
    - Total number of fields – 25,863

Many variations of the same condition
  - DLCO – 827 records
  - History of – 403 records
    - Only ‘History’ and ‘Hx’

Magnitude

This year, over 700 staff hours spent reviewing specify fields for only these 3 sections.

Comorbidities Needing Additional Review
  - Gastrointestinal – 78%
  - Genitourinary – 44%
  - Other – 46%
    - Not completed – 2425 unique values to go
  - 3 fields – over 3000 records for manual review

Next Steps

Phase Two – Review Individual Records
  - Mostly Legacy
  - Review paper records
  - Review full patient details

Phase Three – Contact Centers
  - Request removal of non-significant values
  - Request additional information/changes to unclear values
  - Request corrections to spelling, typos

Ongoing Review
Quiz

True or False

• If I don’t see the checkbox that I want, I can write the info in the other specify and CIBMTR will use it in studies.