Genetics, Healthcare Disparities, and Access to Hematologic Care

David Rice, PhD, MSN, RN, NP, NEA-BC
Director, Education, Evidence Based Practice, and Research
City of Hope National Medical Center

How the Experts Treat Hematologic Malignancies
Las Vegas, NV
March 14, 2018
I do not have anything to disclose
Objectives

• Describe role of genetics, genomics, and genetic testing in healthcare
• Describe healthcare disparity populations
• Describe access to care issues
Definitions

• Genetics
  Study of hereditary and single genes
  Variation of inherited characteristics

• Genomics
  Study of the entire organism’s genes
  Sequence of DNA (adenine[A], cytosine[C], guanine[G], and thymine[T])

• Proteomics
  The study of the structure and function of proteins, including the way they work and interact with each other inside cells

• Pharmacogenomics
  The study of how a person’s genes affect the way he or she responds to drugs. Pharmacogenetics is being used to learn ahead of time what the best drug or the best dose of a drug will be for a person. Also called pharmacogenomics.
# Hematologic Malignancies

## American Cancer Society Data

### Estimated New Cases

<table>
<thead>
<tr>
<th>Males</th>
<th>Females</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prostate</td>
<td>164,690 (19%)</td>
</tr>
<tr>
<td>Lung &amp; bronchus</td>
<td>121,680 (14%)</td>
</tr>
<tr>
<td>Colon &amp; rectum</td>
<td>75,610 (9%)</td>
</tr>
<tr>
<td>Urinary bladder</td>
<td>62,380 (7%)</td>
</tr>
<tr>
<td>Melanoma of the skin</td>
<td>55,150 (6%)</td>
</tr>
<tr>
<td>Kidney &amp; renal pelvis</td>
<td>42,680 (5%)</td>
</tr>
<tr>
<td><strong>Non-Hodgkin lymphoma</strong></td>
<td>41,730 (5%)</td>
</tr>
<tr>
<td>Oral cavity &amp; pharynx</td>
<td>37,160 (4%)</td>
</tr>
<tr>
<td>Leukemia</td>
<td>35,030 (4%)</td>
</tr>
<tr>
<td>Liver &amp; intrahepatic bile duct</td>
<td>30,610 (4%)</td>
</tr>
<tr>
<td><strong>All Sites</strong></td>
<td><strong>856,370 (100%)</strong></td>
</tr>
</tbody>
</table>

### Estimated Deaths

<table>
<thead>
<tr>
<th>Males</th>
<th>Females</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lung &amp; bronchus</td>
<td>83,550 (26%)</td>
</tr>
<tr>
<td>Prostate</td>
<td>29,430 (9%)</td>
</tr>
<tr>
<td>Colon &amp; rectum</td>
<td>27,390 (8%)</td>
</tr>
<tr>
<td>Pancreas</td>
<td>23,020 (7%)</td>
</tr>
<tr>
<td>Liver &amp; intrahepatic bile duct</td>
<td>20,540 (6%)</td>
</tr>
<tr>
<td><strong>Leukemia</strong></td>
<td><strong>14,270 (4%)</strong></td>
</tr>
<tr>
<td>Esophagus</td>
<td>12,850 (4%)</td>
</tr>
<tr>
<td>Urinary bladder</td>
<td>12,520 (4%)</td>
</tr>
<tr>
<td><strong>Non-Hodgkin lymphoma</strong></td>
<td>11,510 (4%)</td>
</tr>
<tr>
<td>Kidney &amp; renal pelvis</td>
<td>10,010 (3%)</td>
</tr>
<tr>
<td><strong>All Sites</strong></td>
<td><strong>323,630 (100%)</strong></td>
</tr>
</tbody>
</table>

Siegel et. al. Cancer Statistics, 2018
Genetics and genomic events

- National Human Genome Research Institute formed
- BRCA1/2 genetic testing commercially available
- 90% of Human Genome Project is completed
- Large rearrangement testing BRCA1/2 genes approved for coverage by Medicare


- Pedigree nomenclature published
- Expert panel genetics and genomics in nursing established by DHHS
- The Genetic Information Nondiscrimination Act is passed
- Next generation sequencing allows for ordering multiple genes or panels of genes

1998 – 2014 – ongoing development of genetic and genomic competencies for nursing science

Oncology Nurse Generalist Competencies P. 679
Care Plans Among Low-Income Survivors P. 692
Toxicities in MAPK Pathway—Targeted Therapies P. 699
A Nurse's Genetics and Genomics Journey P. 715
Accelerating Precision Medicine P. 722
A Crossroads in Ethics and Genetics P. 730
Principles and Relevance of Pharmacogenomics P. 739
Integration of Genomics Education P. 747

Genetics and Genomics
This issue includes a five-article section on genetics and genomics, focusing on how the field is reshaping oncology care and the role of the nurse.
Human cancer exomes sequenced

- Glioblastoma (35)
- Head and Neck Cancer (66)
- Non-Hodgkin Lymphoma (74)
- Lung Cancer (Non-Small Cell) (147)
- Lung Cancer (Small Cell) (163)
- Breast Cancer (33)
- Esophageal Adenocarcinoma (57)
- Esophageal Squamous Cell Carcinoma (79)
- Hepatocellular Cancer (39)
- Gastric Cancer (53)
- Colorectal Cancer (66)
- Ovarian Cancer (42)
- Endometrial Cancer (49)
- Pancreatic Cancer (45)
- Prostate Cancer (41)
- Chronic Lymphocytic Leukemia (12)
- Acute Myeloid Leukemia (8)
- Melanoma (135)
- Glioblastoma (14)
- Medulloblastoma (8)
- Rhabdoid Cancer (4)
- Neuroblastoma (12)
- Acute Lymphocytic Leukemia (11)
Adenocarcinoma

Mutations
- PTEN
- HER2
- KRAS
- EGFR
- BRAF
- PIK3CA
- STK11
- MAP2K1
- AKT-1
- CDKN2A
- MDM2
- MET

Amplifications
- MET
- EGFR
- CRKL

Translocations
- RET
- NTRK1
- ALK
- ROS1
- AXL

Altered pathways
- AMP-dependent protein kinase
- MAPK
- Wnt
- P53

Immune subsets
- PD1
- PDL1

Hensing, Mambetsariev, Salgia; 2017
## Targets in hematology

<table>
<thead>
<tr>
<th>Actionable target</th>
<th>Cancer type</th>
</tr>
</thead>
<tbody>
<tr>
<td>ALK</td>
<td>Large cell lymphoma</td>
</tr>
<tr>
<td>BCL-2</td>
<td>Chronic lymphocytic leukemia</td>
</tr>
<tr>
<td>BCR-ABL</td>
<td>Chronic myelogenous leukemia</td>
</tr>
<tr>
<td>FLT3</td>
<td>Acute myeloid leukemia</td>
</tr>
<tr>
<td>Histone deacetylase</td>
<td>Cutaneous T cell lymphoma</td>
</tr>
<tr>
<td></td>
<td>Multiple myeloma</td>
</tr>
<tr>
<td>Programmed cell death protein 1 (PD-1)</td>
<td>Hodgkin lymphoma</td>
</tr>
</tbody>
</table>
Considerations for genetic risk assessment and counseling

- Pathogenic variant in family
- Patterns of cancer in family
- Psychological impact of test results
  - Multigene testing
    - Actionable mutations / targets
    - Non-actionable mutations / targets
    - Direct to consumer tests
- Ethical implications
  - Beneficence, nonmaleficence, autonomy, justice
Features suggesting hereditary cancer

- Early age at onset (e.g. premenopausal breast cancer)
- Multiple primary cancers in an individual (e.g. colorectal and endometrial)
- Bilateral cancer in paired organs or multifocal disease (e.g. bilateral breast cancer or multifocal renal cancer)
- Clustering of same cancer type in close relatives (e.g. mother, daughter, sisters with breast cancer)
- Cancers occurring in multiple generations (i.e. autosomal dominant inheritance)
- Rare tumors (e.g. retinoblastoma, adrenocortical carcinoma, granulosa cell tumor of the ovary, ocular melanoma, or duodenal cancer)
- Occurrence of epithelial ovarian, fallopian tube, or primary peritoneal cancer
- Unusual presentation (e.g. male breast cancer)
- Uncommon tumor histology (e.g., medullary thyroid carcinoma)
- Rare cancers associated with birth defects (e.g., Wilms tumor and genitourinary abnormalities)
- Ethnicity when strong founder effect is present in the population (e.g. Ashkenazi heritage and BRCA1/2 pathogenic variants).

https://www.cancer.gov/about-cancer/causes-prevention/genetics
Genetic testing may be considered when ...

- Patient’s personal history (including ethnicity) and/or family history are suspicious for a genetic predisposition to cancer
- The genetic test has sufficient sensitivity and specificity to be interpreted
- The test will impact the individual’s diagnosis, cancer management or cancer risk management, and/or help clarify risk in family members
The National Institutes of Health (NIH) defines diversity as “the range of human differences, including but not limited to race, ethnicity, gender, sexual orientation, age, social class, physical ability or attributes, religious or ethical value system, national origin, and political beliefs.”
Visible / Public Identities

- Age
- Sex
- Gender expression
- Physical appearance
- Race
- Class
- Health / ability

Invisible Identities

- Ethnicity / national origin
- Gender Identity
- Politics
- Religion
- Relationship status
- Employment status
- Personal habits
- Communication style
- Educational background
- Work experience
- Socioeconomic status
FIGURE 4-1 Level of focus on diversity among state Action Coalitions.

NOTE: This map is based on aggregated responses from states about their Action Coalition’s focus on racial/ethnic and gender diversity in nursing. State scores were divided into high, medium, and low levels of focus. There were not enough respondents from Delaware or Michigan to calculate a score.

FIGURE 1-3 Priority focus area for each state Action Coalition.

NOTES: Survey respondents categorized the amount of focus given to each priority area. State scores were aggregated, and the highest score was identified as the top priority. The number of responses from Alaska, Delaware, Indiana, Michigan, and North Dakota was insufficient for calculation of scores. APRN = advanced practice registered nurse; BSN = bachelor of science in nursing.

Underserved Populations
Cancer Access Healthcare Disparities
Underserved Populations
Cancer Access Healthcare Disparities
Healthcare Disparity Populations

Defined:
In Healthy People 2020, a health disparity is defined as “a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion.”

http://www.healthypeople.gov/sites/default/files/Phasel_0.pdf
Disparities / costs

- Estimated costs to the nation
  - $50.3 billion in excess healthcare expenditures
  - $35 billion in illness-related lost productivity
  - $309 billion in premature death.
- Racial and ethnic minorities disproportionately represent populations bearing the greatest burdens.

Figure 4.
Population Without Health Insurance Coverage by Single Year of Age: 2013

Note: The bar for age 0 (zero) is not shown in this figure.

For information on confidentiality protection, sampling error, nonsampling error, and definitions, see <ftp://ftp2.census.gov/programs-surveys/cps/techdocs/cpsmar14.pdf>.

Figure 1.2. Percentage of persons under age 65 without health insurance coverage at the time of interview, by age group and sex: United States, January–June 2016

NOTES: Data are based on household interviews of a sample of the civilian noninstitutionalized population. A person was defined as uninsured if he or she did not have any private health insurance, Medicare, Medicaid, Children’s Health Insurance Program, state-sponsored or other government-sponsored health plan, or military plan at the time of interview. A person was also defined as uninsured if he or she had only Indian Health Service coverage or had only a private plan that paid for one type of service, such as accidents or dental care. The data on health insurance status were edited using an automated system based on logic checks and keyword searches. The resulting estimates of persons not having health insurance coverage are generally 0.1–0.3 percentage point lower than those based on the editing procedures used for the final data files. The analyses excluded the 1.1% of persons with unknown health insurance status. See Technical Notes for more details.
Figure 1.3. Age-sex-adjusted percentage of persons of all ages without health insurance coverage at the time of interview, by race and ethnicity: United States, January–June 2016

NOTES: Data are based on household interviews of a sample of the civilian noninstitutionalized population. A person was defined as uninsured if he or she did not have any private health insurance, Medicare, Medicaid, Children’s Health Insurance Program, state-sponsored or other government-sponsored health plan, or military plan at the time of interview. A person was also defined as uninsured if he or she had only Indian Health Service coverage or had only a private plan that paid for one type of service, such as accidents or dental care. The data on health insurance status were edited using an automated system based on logic checks and keyword searches. The resulting estimates of persons not having health insurance coverage are generally 0.1–0.3 percentage point lower than those based on the editing procedures used for the final data files. The analyses exclude the 1.0% of persons with unknown health insurance status. Estimates are age-sex-adjusted using the projected 2000 U.S. population as the standard population and three age groups: under 18 years, 18–64, and 65 and over. See Technical Notes for more details.
Figure 5.
Percentage of the Population 65 Years and Older, in Poverty, and Participating in Medicare and Medicaid by Race and Hispanic Origin: 2013

For information on confidentiality protection, sampling error, nonsampling error, and definitions, see <ftp://ftp2.census.gov/programs-surveys/cps/techdocs/cpsmar14.pdf>.

FIGURE 2-2 Hispanics and non-Hispanics as a percentage of the U.S. population, 2000-2050.

NOTE: For the years 2010-2050, data are from the U.S. Census Bureau’s 2008 National Population Projections. For 2000, data are from Congressional Research Service extractions from the U.S. Census Bureau’s 2004 U.S. Interim National Population Projections.

SOURCE: Shrestha and Heisler, 2011.
Impact of Sexual Orientation and Gender Identity on Cancer Care

• Of the nearly 11 million lesbian, gay, bisexual, and transgender people in the United States
  • Tobacco use higher
  • Alcohol use 3X higher
  • Risk of sexually transmitted disease higher
  • Eating disorders / obesity
  • Elevated risk depression, anxiety, psychological distress, suicidality
  • Higher cancer risks and lower cancer screening rates
  • Increased challenges in survivorship
POVERTY AND ITS IMPACT ON LGBT HEALTH

• 1/3 of LGBT people are uninsured
  • 34% of gay men
  • 31% of lesbians
  • 29% of bisexual people

• 2/3 of the uninsured had been without coverage for more than 2 years

• Nearly 40% of uninsured respondents carry medical debt

• 44% of the insured put off medical care because they couldn’t afford it
Physical environment

DISCRIMINATION BASED ON ECONOMIC STATUS AND HOMOPHOBIA

Discrimination and substandard care: Lesbian, gay or bisexual (LGB) and transgender or gender-nonconforming (TGNC)
The highest-, lowest-ranked states for health care

- **Access to care (33%)**
  - Six metrics, including health insurance enrollment, adult and child wellness visits, and health care affordability

- **Health care quality (33%)**
  - Three metrics: Medicare quality, CMS nursing home citations, and hospital readmission rates

- **Public health (33%)**
  - Six metrics, including infant mortality, overall mortality, smoking, suicide, and obesity rates

[https://www.advisory.com/daily-briefing/2017/03/06/state-health-rankings?WT.mc_id=Email|DailyBriefing+Headline|DBA|DB|2017Mar06|SurveyDB2017Mar06| || |&elq_cid=1515155&x_id=003C000001gGxUJAW](https://www.advisory.com/daily-briefing/2017/03/06/state-health-rankings?WT.mc_id=Email|DailyBriefing+Headline|DBA|DB|2017Mar06|SurveyDB2017Mar06| || |&elq_cid=1515155&x_id=003C000001gGxUJAW)
The highest-, lowest-ranked states for health care

<table>
<thead>
<tr>
<th>Highest-Ranked States</th>
<th>Lowest-Ranked States</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hawaii</td>
<td>41. Indiana</td>
</tr>
<tr>
<td>Massachusetts</td>
<td>42. Tennessee</td>
</tr>
<tr>
<td>Minnesota</td>
<td>43. Wyoming</td>
</tr>
<tr>
<td>New Hampshire</td>
<td>44. Kentucky</td>
</tr>
<tr>
<td>Iowa</td>
<td>45. Louisiana</td>
</tr>
<tr>
<td>Vermont</td>
<td>46. West Virginia</td>
</tr>
<tr>
<td>Rhode Island</td>
<td>47. Alabama</td>
</tr>
<tr>
<td>New Jersey</td>
<td>48. Oklahoma</td>
</tr>
<tr>
<td>Washington</td>
<td>49. Mississippi</td>
</tr>
<tr>
<td>California</td>
<td>50. Arkansas</td>
</tr>
</tbody>
</table>

[Source](https://www.advisory.com/daily-briefing/2017/03/06/state-health-rankings?WT.mc_id=Email|DailyBriefing+Headline|DBA|DB|2017Mar06|SurveyDB2017Mar06|||&elq_cid=1515155&x_id=003C000001gGxUJAW)
FIGURE 1. Cancer Death Rates (per 100,000 Population) by Congressional District and Sex, 2002 to 2011.
Figure 1. County-Level Mortality From Neoplasms

A Age-standardized mortality rate from neoplasms, both sexes, 2014

Deaths per 100,000 population

B Percent change in age-standardized mortality rate from neoplasms between 1980 and 2014, both sexes

C Age-standardized mortality rate from neoplasms over time

A. Age-standardized mortality rate for both sexes combined in 2014. B. Relative percent change in the age-standardized mortality rate for both sexes combined between 1980 and 2014. In panels A and B, the color scale is truncated at approximately the first and 95th percentiles as indicated by the range given in the color scale. C. Age-standardized mortality rate in 1980, 1990, 2000, and 2014. The bottom border, middle line, and top border of the boxes indicate the 25th, 50th, and 75th percentiles, respectively, across all counties. Whiskers, the full range across counties, and circles, the national-level rate.
When compared to other high-income countries, the US provided less DAH per person and less DAH per national income.
FIGURE 2-1 Distribution of the projected older population by age in the United States, 2010 to 2050.
NOTE: Vertical line indicates the year that each age group is the largest proportion of the older population. Data are from the U.S. Census Bureau’s 2008 National Population Projections.
According to the National Institute on Minority Health and Health Disparities, a health disparity is defined as a health difference that adversely affects disadvantaged populations, based on one of more of the specified health outcomes:

- Higher incidence and/or prevalence of disease and/or disorders;
- Premature and/or excessive mortality in diseases where the populations differ;
- Greater burden of disease demonstrated with metrics such as reduced quality of life or disability-adjusted life years; or
- Poorer daily functioning.

A shorter life expectancy of 12 years on average for LGB individuals in communities with high vs. low stigma.

The Health Consequences of Hate

Research by Mark Hatzenbuehler suggests discriminatory laws in North Carolina and Mississippi are a life or death matter for LGBT people living there.

It’s been ten months since Obergefell v. Hodges, the landmark Supreme Court ruling that guaranteed sex-sex couples the right to marriage, a decision embraced by most of the country. While LGBT rights have increasingly become part of the nation’s human rights fabric, isolated instances of pushback—particularly in the American South—have resulted in legislation that critics say discriminates against LGBT people.

In Mississippi, HB1523 permits businesses to refuse people services on religious grounds. The law actually specifies these beliefs, that marriage is between a man and a woman, that sex is reserved for heterosexual marriage, and that gender is determined at birth as male or female. As one example of how the law could work outlined in a Columbia Law School report, a school mental health counselor would be permitted to refuse to work with an at-risk student who identifies as gay. The North Carolina law, HB2, bans anti-discrimination protections based on sexual orientation and requires that in public buildings and schools, transgender individuals use bathrooms corresponding to their gender as assigned at birth.
Healthcare Disparity Populations
Access to care

Of the interconnected cancer metrics, quality, safety, outcomes, cost, insurance status, access — **access** may be the most important:

- Rural / mountainous / remote geographic areas
  - Older cancer populations
  - Negligible public transportation
  - Car / driver / caregiver / afford gas?
  - Distance to travel

- Access to cancer care
  - Molecular testing / liquid biopsies / prognostic markers
  - Diagnostic imaging
  - Supportive care / symptom management during treatment
  - Survivorship programs often unavailable to patients in rural and low-income areas
Price and Cost Pressures Squeezing Profit Margins

- **Downward Pricing Pressure**
  1. Direct reimbursement pressure
  2. Federalism and state-based coverage reform
  3. Dilution of commercial coverage
  4. Deregulation and the new era of competition
  5. Shifting demographics and payer mix evolution

- **Upward Cost Pressure**
  6. Rising pharmaceutical costs
  7. Uncontrolled labor spending growth
  8. Increasing reliance on IT enablement
  9. Growth in purchased services

Source: Health Care Advisory Board interviews and analysis.
Retail Clinics Expected to Continue Growing

## Clinics Drive Utilization, but Minimally Offset ED Utilization

<table>
<thead>
<tr>
<th>Retailer</th>
<th>Operational Retail Clinics</th>
</tr>
</thead>
<tbody>
<tr>
<td>minuteClinic</td>
<td>1,105</td>
</tr>
<tr>
<td>Walgreens Healthcare Clinic</td>
<td>400+</td>
</tr>
<tr>
<td>The Little Clinic</td>
<td>213</td>
</tr>
<tr>
<td>RediClinic</td>
<td>91</td>
</tr>
<tr>
<td>Walmart</td>
<td>75(^3)</td>
</tr>
</tbody>
</table>

### Increased Utilization in Health Care Clinics Offsets Savings

- **Replace ED Visits**: 3%
- **Replace Physician Visits**: 39%
- **New Visits**: 58%

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2800
Estimated total number of retail clinics\(^1\) in the US.

2X
There are approximately double the number of retail clinics as there were in 2012.

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Urgent Care Ripe for Consolidation and Diversification

7,546
Estimated number of urgent care clinics in operation in the US in 2018

<5%
Maximum percentage of total industry revenue generated by any of the largest players

Urgent Care Beginning to Offer Ongoing Primary Care Services

Continued growth likely in urgent care centers offering ongoing primary care to bolster referrals, relieve primary care offices, and manage population health

Operator
Concentra
MedExpress
Dignity Health
Doctors Express
NextCare

Operational Urgent Care Centers
300+
180
174
163
137

Healthcare Disparity Populations
Access to cancer care

Healthcare Disparity Populations
Access to care

- Participation in clinical trials – nationwide 3%
  - Cost – number one cited reason to not participate
  - Other logistics
    - Travel to trial location
    - Finding lodging
    - Securing child care at home
    - Accounting for lost pay (patient and caregiver)
- Additional considerations
  - Lack of available trial for diagnosis / stage
  - Narrow inclusion / exclusion criteria
  - Patient / family overwhelmed by new diagnosis and treatment information
  - Limited health literacy and understanding
    - Complicated consent forms
    - Complicated surveillance requirements
  - Challenges engaging ethnic / racial diverse patients
Workforce Issues – HCT in 2020


- Increasing number of diverse and medically underserved populations
  - Elderly, ethnic minorities, primary language other than English
- Requires culturally competent workforce
- BMT health professionals role in:
  - Trust – fundamental part of patient – provider relationship
  - Patient and family education
  - Treatment adherence

Factors which impact access to HCT

**Social**
- Age
- Ethnicity / Race
- Language
- Culture
- Health Literacy
- Patient / family attitudes
- Caregiver availability

**Donor Availability**

**Economic**
- Socioeconomic status
- Education
- Number of wage earners
- Employment status
- Insurance coverage
- Place of residence
- Transplantation

**Provider**
- Physician referral
- Provider attitudes / biases
- Provider expertise
- Provider diversity

**Healthcare system**
- Limited number of HCT centers
- Workforce shortage
- Capacity limitations
- Infrastructure issues

**Access**
Workforce Issues

NMDP (2012) reporting on Hematopoietic Cell Transplant in 2020 (year one of two):

- Investigate strategies to increase workforce recruitment, retention, and improve work / life balance across physician, nursing, APP workforces. This aspect includes women, racial / ethnic minorities, persons with disabilities, and other individuals who have been underrepresented in science and graduate schools.
- Assess impact of current state and federal legislation on the delivery of HCT.
- Make available to hospital administrators data on the norms in HCT staffing and bed capacity across regions of the US.
- Raise awareness of the optimal timing for HCT referral.
Workforce Issues (continued)

- Identify and disseminate best practices for caregiver support and education through all phases of transplant
- Develop a set of model transplant insurance benefits for payers
- Establish a Pharmacy Workforce Working Group to ensure that oncologic pharmacists specializing in HCT are engaged in meeting the expected workforce need
- Develop priorities for a combined Facilities / Bed Capacity and Care Delivery Model Working Group
- Engage stakeholder organizations essential to achieving Working Group outcomes for Year II
<table>
<thead>
<tr>
<th>Identified System Challenges</th>
<th>Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Physician Workforce</strong></td>
<td></td>
</tr>
<tr>
<td>• Physician shortage–Recruitment–Retention–Work environment</td>
<td></td>
</tr>
<tr>
<td>• Workforce diversity</td>
<td>• Validate work effort benchmarks</td>
</tr>
<tr>
<td>• Workforce diversity</td>
<td>• Conduct transplant physician census to characterize workforce</td>
</tr>
<tr>
<td>• Target medical schools and residency programs as part of a recruitment strategy</td>
<td></td>
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<tr>
<td><strong>Advanced Practice Professional (APP) Workforce</strong></td>
<td></td>
</tr>
<tr>
<td>• Care team work models</td>
<td>• Better define the APP role within HCT</td>
</tr>
<tr>
<td>• APP shortage–Recruitment–Retention–Work environment</td>
<td>• Increase exposure to HCT as a career path for students and practicing APPs–Develop “Blood and Marrow Transplant (BMT) 101” presentation for APP graduate programs</td>
</tr>
<tr>
<td>• Workforce diversity</td>
<td>• Improve quality of work life–Identify ways to prevent burnout and better characterize the APP workload</td>
</tr>
<tr>
<td></td>
<td>• Engage administration in exploring compensation and benefits package options to support continuing education, professional memberships, etc.</td>
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<tr>
<td></td>
<td>• Establish national Physician Assistant ASBMT SIG*</td>
</tr>
<tr>
<td></td>
<td>• Partner with ASBMT* to create orientation and education standards for APPs entering the field</td>
</tr>
<tr>
<td>Identified System Challenges</td>
<td>Recommendations</td>
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<tr>
<td>------------------------------</td>
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</tr>
<tr>
<td><strong>Nursing Workforce</strong></td>
<td></td>
</tr>
<tr>
<td>• Nursing shortage—Recruitment—Retention—Work environment</td>
<td>• Partner with nursing organizations to increase exposure to HCT nursing by promoting:—Student internship/externship programs—Successful models of career mentorship programs—ONS* “Fundamentals of Blood and Marrow Transplant” Web course—Identify funding sources for HCT nurse scholarship(s) and Professional development/continuing education</td>
</tr>
<tr>
<td>• Educational needs</td>
<td></td>
</tr>
<tr>
<td>• Workforce diversity</td>
<td></td>
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<tr>
<td><strong>Facilities/Bed Capacity</strong></td>
<td></td>
</tr>
<tr>
<td>• Current capacity limitations—Inpatient, outpatient, infusion therapy, etc.</td>
<td>• Collect data from transplant programs—Provide trend data on growth of transplants to support expansion initiatives—Identify best practices to emulate</td>
</tr>
<tr>
<td>• Distribution of HCT beds in the United States</td>
<td>• Partner closely with Care Delivery Model Working Group—Establish specific elements of care models—Centers with high patient volume per bed as benchmark of efficiency and effectiveness</td>
</tr>
<tr>
<td>• Care delivery model impact on physical space requirements</td>
<td>• Assist expansion planning by disseminating success stories, partnering with program administrators or through use of external consultants</td>
</tr>
<tr>
<td>• Increase in patient volume—Demand on patient care/support services—Shortage of temporary patient housing near the transplant center</td>
<td>• Create a data set of growth models</td>
</tr>
<tr>
<td>• Shortage of temporary patient housing near the transplant center</td>
<td>• Help in developing measures of successful growth</td>
</tr>
<tr>
<td>Identified System Challenges</td>
<td>Recommendations</td>
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<td>------------------------------------------------------------------------</td>
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<tr>
<td><strong>Care Delivery Model</strong></td>
<td></td>
</tr>
<tr>
<td>• Late timing for referral to transplant consultation</td>
<td>• Work with professional medical organizations to highlight optimal transplant timing—Use payor data—NMDP* Network Engagement team to inquire about late referrals on site visits</td>
</tr>
<tr>
<td>• Insufficient HLA typing at time of diagnosis</td>
<td>• Develop mechanism for patients’ physicians to access patient records</td>
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<tr>
<td>• Inadequate caregiver support</td>
<td>• Explore models for providing posttransplant care (e.g., telemedicine, satellite clinics)</td>
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<tr>
<td>• Coordination of post-transplant patient care</td>
<td>• Partner with Medicare/payors to structure reimbursement care in a variety of settings</td>
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<tr>
<td>• Transition to outpatient care model requires optimal workflows</td>
<td>• Identify housing options near transplant center</td>
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<tr>
<td>• Effective use of Residents and Fellows on the care team</td>
<td>• Provide recommendations on staffing and design of outpatient facilities</td>
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<td></td>
<td>• Develop patient and caregiver education materials and training programs</td>
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<tr>
<td><strong>Financial</strong></td>
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<tr>
<td>• Benefits vary significantly and are inadequate—Financial barriers for patients</td>
<td>• Identify an essential set of HCT benefits which includes all components of transplant</td>
</tr>
<tr>
<td>• Medicaid transplant benefits—Vary significantly and inadequate in many states</td>
<td>• Develop a standard list of transplant codes and coding guidance</td>
</tr>
<tr>
<td>• Medicare coverage and reimbursement—Inadequate—Growing problem as patient volume increases</td>
<td>• Review utilization management/authorization processes for potential areas to streamline procedures—Reduce administrative delays on both sides</td>
</tr>
<tr>
<td>• Inadequate search coverage</td>
<td>• Plan outreach strategies to all types of payors (e.g., self-funded accounts, reinsurers and health plans)—Provide tools and information for decision making</td>
</tr>
</tbody>
</table>

*NMDP* Network Engagement team
Summary

- Aging population
  - Frailty, treatment risks / outcomes considerations
- Increasing cancer incidence
- Treatments with longer disease control
- Increasingly expensive technologies
- Future of genetic testing and resultant treatment decisions
- Continued schism wealth and poverty / access and lack of access
THE DIFFERENCE MATTERS
EQUALITY VS EQUITY