



MCA Cancer Plan Revision Meeting Summary

Survivorship Workgroup

11:30 a.m. – 1 p.m., May 18, 2016

Participants: Ruth Bachman, Tia Bastian, Anne Blaes, Lynn Everling, Kristen Kopski, Scott Nelson, Katie Ruddy, Emma Sacco, Lindy Yokanovich

MDH Staff Liaison: Jeanne Steele

Location: Hope Lodge, Minneapolis, MN and by conference line

Agenda Topic	Key Points Raised	Next Steps
<p>Introductions & Welcome</p>	<p>Co-chair Anne Blaes welcomed Emma Sacco to the group, and explained that she was working closely with Nancy Hutchison on the rehabilitation topic. Something came up for co-chair Syndal Ortman that morning, so she was unable to participate in person. However, she planned to call in, if able. Anne reviewed the purpose of the workgroup and progress to date, and thanked Nancy Hutchison and Lindy Yokanovich for their impressive work on the issues forms. She told the team not to sweat it if they had nothing written down; this would be a working/brainstorming meeting.</p>	<p>NA</p>
<p>Cancer Rehabilitation & Physical Impairment</p>	<p>Emma highlighted several of the articles cited in the draft issues statement. They were selected because they explain why physical rehabilitation is so important for cancer patients.</p> <p>Challenges: Cancer survivors are not being referred for existing services; there are not enough qualified professionals to meet the needs; many people are excluded from this care for sociocultural reasons.</p> <p>Barriers: Very few med school programs address PMR; payment systems are not set up properly for patients to get the right services at the right time; CoC distress screening standards do not include physical impairment. Each institution seems to do distress screening a little bit differently. Allina uses Promise 10 tool which</p>	<p>Explore other programs and potential partners, potentially in other domains:</p> <ul style="list-style-type: none"> • Courage Center • National disease organizations • Public-private partnerships such as Lifetime Fitness <p>Patients need to be empowered to know what to ask for.</p>

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	<p>evaluates both physical and psychosocial distress. Most think there's not enough screening or appropriate referrals based on screening.</p> <p>Other issues:</p> <ul style="list-style-type: none"> • No standard criteria for community exercise trainers • Physical therapists say the docs are not sending patients • Community organizations (e.g., Rochester YMCA) need funding to offer programs • Medicare plans do not universally pay for gym memberships 	<p>Physical rehab needs to be “hard-wired” into a patient’s plan of care from the first visit.</p> <p>ACTION: Emma Sacco, Nancy Hutchison and Lynn Everling to continue work on reporting form. They will loop in Liz Moe.</p>
<p>Financial and Legal Issues</p>	<p>Lindy highlighted key points in the issue statement she drafted. Financial fallout and legal issues stemming from a cancer diagnosis “cannot be overstated.” They often mirror recognized social determinants of health (housing, income, employment, food insecurity)</p> <p>Problems associated with issue:</p> <ul style="list-style-type: none"> • Doctors and lawyers work in silos – lawyers are over here; doctors are over there. • Different vocabularies: Lawyers would never use the term “social determinants of health,” but it is lawyers who can help. • Lack of paid leave, limits on paid leave, or lack of provisions for intermittent leave e.g., FMLA, are big problems. Keeping people employed throughout their treatment often requires getting a lawyer involved with HR. • High deductibles wipe out many – 14% of MN have high deductible plans, highest percentage in country. • Unfunded legal aid programs – 80% of people who qualify turned away. • Too-long wait periods: 5 months for Social Security Disability Income; 29 months for Medicare coverage to begin ff. determination of eligibility 	<ul style="list-style-type: none"> • Look for successful, concrete models nationally. In NYC, every hospital has legal clinic on site. Boston & Omaha are other cities that are doing it. • Explore whether hospitals’ requirement to provide ‘community benefits’ is way to fund legal-medical services <p>ACTION: Lindy will continue work on draft, with input from Nancy, Ruth Bachman, Shari Hahn and Liz Moe.</p>
<p>Patient Navigation</p>	<p>Challenge: To provide the right information to the patient at the right time – even if it’s a weekend.</p> <p>Barriers:</p>	<p>Explore what the “five pillars of health” are: social, emotional, financial,</p>

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	<ul style="list-style-type: none"> • Hard to keep services tied to the patient. Lots of services available, but not consistently available across the state • At diagnosis, patients need to make life-altering decisions in short period of time • Care coordination/patient navigation mostly focused on medical system • Shortage of social workers who often make referrals that address social determinants • How do you get paid for this? Nurse care coordinators' time not reimbursable. Allina stopped billing for care coordination; too burdensome for too little return. • Patients are afraid of asking dumb questions. • Every case is different, but there are certain things that are similar for everyone. <p>What's needed: Patient navigation tool</p> <p>Different types of info needed at 5 key points:</p> <ol style="list-style-type: none"> 1. At diagnosis – Info needs to be really simple; patient is going to be in shock. Can often be a patient's regular doctor who shares the news. 2. First medical institution point of contact – 3. 1st appointment 4. Resource materials – also referral for medical team 5. Aftercare/survivorship <p>Possible solutions: A handbook; a website, a wiki.</p>	<p>spiritual. . .? Would this be useful way to organize a handbook for cancer patients?</p> <p>Learn more about what it would take to set up a wiki. Who would be in charge of editorial oversight? Would it target providers or patients? Would there need to be two – one for each?</p> <p>ACTION: Kris will work with Lynn, Scott Nelson and Tia Bastian to sort out details. They will communicate by email.</p>
Survivor Care Plans	Katie and Anne got together and roughed out key points last week.	ACTION – Anne and Katie will circulate draft in next couple of weeks.
Palliative Care Services	Still some confusion about who is handling this.	ACTION – Anne will touch back with Joe Leach to see if Treatment's got it covered; Jeanne will see whether the newly formed Advance Care Planning/Hospice workgroup wants to

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		be involved; Survivorship will tackle if no one else does.
Support Services	<p>Possibility of merging Patient Navigation and Support Services was broached. Discussion turned to types of resources available.</p> <p>Challenges: Community services, national services – How do you pull this labyrinth of things together? Current plan called for assessing and addressing gaps in resources statewide. Tia inquired whether it was ever conducted. Answer: Those present were not sure. A searchable website of resources was created by Alliance, but discontinued 3-4 years ago because too difficult/labor intensive to maintain. Supports for survivors must be culturally appropriate and sensitive to cultural differences. Tia is aware of a bunch of resources for the native community that don't show up on the national websites, etc. But it's the same list. . . Something modeled after Gawande's <i>Checklist Manifesto</i> might work as patient navigation tool. Going forward: Next cancer plan can be viewed as "kind of a pipeline." It will be a 10-year plan. People shouldn't leave things out because they aren't do-able in the short term. Some things take a long time to get moving. Computer applications that do many of the things we're talking about are "being built as we speak."</p>	ACTION: Scott will take lead on a Support Services draft. He and Ruth, Lindy and Tia should determine whether Support Services should remain separate, or whether it should be combined with Patient Navigation.
Next Steps	<ul style="list-style-type: none"> • Anne will set up a call in a couple of weeks to discuss a draft, re: Survivor Care Plans. • Subgroups should complete their issue analysis and objectives and strategies forms no later than June 15. Email forms to Jeanne.steele@state.mn.us. • Jeanne will compile and recirculate for review prior to June 22 meeting. • Subgroups are responsible for figuring out how best to work together. • Draft documents can be posted on the Web (mncanceralliance.org\cancer-plan-update\survivorship) if subgroups want input from broader group of stakeholders. 	

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Next meeting: June 22, 11:30 a.m. – 1 p.m., Hope Lodge

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