Background: Social media is increasingly used by patients for cancer information and psychosocial support. Certain information/features may be more desired in a new hospital-based social media cancer resource; these may vary between adolescent-young adult (AYA; age <40) and non-AYA (age 40+).

Methods: Using age specific sampling, cancer patients across all disease sites completed a cross-sectional survey of demographics, health status, and social media/online resource use for cancer education. Clinical information was abstracted.

Results: Of 127 AYA cancer patients and 193 non-AYA (older adult) patients, 100% (AYA) and 92% (non-AYA) stated they use the internet (p < 0.001); 95% AYA and 72% non-AYA used social media (p < 0.001). When asked about attitudes towards social media, 64% AYA and 50% non-AYA believed they could judge social media information quality; 18% AYA and 18% non-AYA recommended use of current social media resources. When asked what types of features they would want in an online resource for their cancer care, both AYA and non-AYA most frequently reported wanting to view their own personal health records (82% AYA/63% non-AYA), followed by an online library of cancer resources (73% AYA/56% non-AYA), ability to communicate with healthcare professionals (73% AYA/55% non-AYA), and appointment reminders (72% AYA/58% non-AYA). The most frequently desired information for both groups were treatment options (61% AYA/56% non-AYA), causes/risk factors/symptoms (65% AYA/56% non-AYA), and prognosis/outcomes (52% AYA/46% non-AYA). The largest difference in information preference between the two age groups were in wellness programs (62% AYA/39% non-AYA) and work return (42% AYA/20% non-AYA) (p < 0.001).

Conclusions: There is significant agreement between AYA and non-AYA patients in the most desired information and features they want in a social media resource, though AYA patients wanted a greater number of features. Patients’ desired information suggested a patient preference for more autonomy and insight into their disease, regardless of age. There is a lack of satisfaction with current social media resources. A single set of informational tools can therefore be developed for all adults.

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What information and features do young and older adults with cancer want in their hospital-based social media cancer resource?

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