

Company Culture



Involving patients to achieve a Patient Centric Culture

1 Steps towards a patient centric company

There are several approaches to installing or reinforcing culture in an organisation, but some steps are common to most methodologies:

Involve leadership:

As good examples come from the top, the leadership of the organisation and of all departments are the first that need to be convinced of the patient-centric culture. A strategy to reach the desired level of patient centricity needs to be elaborated. KPIs and CSF could be elaborated.

A burning platform to increase desire or urgency:

Create a burning platform to convince people about the need for change and make them want to change. Stories from patients about current issues or about how a difference for patients has been made in the past, will help to create this desire or sense of urgency.

Knowledge, ability, quick wins

People need to know what to change. Sometimes small actions can have a big impact on patients or patient organisations. Sitting down and brainstorming about possible actions will identify the low-hanging fruit.

Reinforce or maintain

Demonstrating the impact of the changes helps them need to be sustained. Patient organisations can provide feedback on the (measurable) impact of the changes so far.



2 Tools

While the Patient Expert Center is not a consulting agency and will not develop a culture change strategy, we can suggest several tools to involve patients.

Focus groups

Focus groups can generate ideas that, with a few simple interventions, can improve patient orientation in a particular department or division. Most apt to the phase “Knowledge, ability, quick wins”

Individual patient meeting

A one-to-one chat with a patient will shed a new light on daily activities and renew your knowledge of why your organization exists. Good tool to involve leadership.

Patient testimonial

Although not in the form of a dialogue, a patient testimonial has a similar effect to the individual patient meeting, but for larger groups. It will (re)raise awareness of the need for patient centricity. It can also highlight the impact of efforts already made to be patient-centred.

Possible topics: what after medication. Do employees know what happens once the therapy is ended?

Good to create a burning platform and to reinforce or maintain the culture.

Follow up on patient centricity

As external party a patient organisation can provide a quantitative measure of progress on patient centricity. For example by carrying out a standardised questionnaire on your organisation's patient centricity on a regular basis. (example in chapter 2 Patient organisation-initiated actions)

Good to Reinforce or maintain the culture.

Challenge sessions

Patient Experts can challenge basic assumptions made by teams to stimulate innovative thinking. This can lead to new findings for treatments.

Involving PEs in projects

Involving Patient Experts in projects, will increase patient centricity, even if the project in itself is not focused on increasing patient centricity. Good experiences with Patient Experts and understanding the value of their input will increase the likelihood of involving Patients Experts again. This can be through (online) questionnaires, interviews, ...

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3 Systematic patient's perspective integration

Initiatives a company could implement to systematically involve patients' perspective in the daily operation of the company:

General

Pharma.be 10 points checklist

Pharma.be elaborated a 10 points checklist as a touchstone to assess whether a company is truly patient-centred. Making sure each checkbox can be ticked through developing the correct processes, will increase the patient centricity of the company.

<https://pharma.be/nl/media/nieuws/klaarheid-en-goede-afspraken-in-samenspraak-met-patientenorganisaties>

<https://pharma.be/fr/medias/actualites/clarte-et-bons-accords-en-consultation-avec-les-associations-de-patients>

Patient organisation SPOC

To facilitate patient organisations to contact the company, a Single Point of Contact (SPOC) should be designated. This SPOC will make sure the right persons inside the company are contacted.

Signature programs

A company can develop a signature program to support patients, patients' relatives, carers, ... Patient Organisations or Patient Experts can highlight some ideas or give feedback on the elaboration.

Patient panel

An organisation could install a patient panel to systematically give feedback on the status of the patient engagement in the company.

Patient Day

A yearly initiative to which patients are invited for testimonials, one2one interviews or ...

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Project management

Project scoring and selection

Scoring each project undertaken in the organisation for patient-centricity or 'warmth' is one way to improve patient-centricity in general. A standardised scorecard developed with patient organisations could be used.

The patient-centricity score of a project should be one of the parameters for deciding which projects to fund.

Involving Patient Experts from the beginning of a project, for example to score a project, is a further step towards patient-centricity.

Project evaluation

Once a project has been completed or milestones have been reached, the patient organisations or patient experts involved in the project can be asked to evaluate the project and the collaboration. This can be via an (online) questionnaire or in-person.

Disease specific

Lifecycle feedback

Patient's feedback should be sought throughout the lifecycle of the product or service, rather than asking patients to describe how a treatment improves their quality of life (QoL) once the product is ready.

For example, in the ideation phase, the patient can be asked what a treatment needs to do to improve their overall lived experience.

A standard list of questions per lifecycle phase would help teams to start these discussions.

Patient pathway

Patient pathways describe the full 'journey' of a patient, from first symptoms to full recovery, chronic disease management or palliative care and end of life.

Creating these pathways for the diseases for which the organisation develops products or services will enhance understanding of the patient perspective and identify opportunities for improvement.

Of course, patients need to be involved in the creation and maintenance of such a pathway, together with HCPs, other product or service companies, government agencies ...

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Patient enquiries

Reading questions from patients and asking how the organisation can help or has helped to resolve them. Encourage patients and patient organisations to ask questions directly to the organisation.

Every evening during his presidency, Obama read 10 letters from random citizens and asked himself how he was helping them.

Human Resources

New employee training

A training program for new employees could be developed in which a meeting with a patient or Patient Expert is included. This can be a testimonial for small groups of new employees.

Evaluation criteria

Patient centricity should be part of the evaluation criteria of all employees. Not only of the market access department or medical affairs.

For example, the finance department (fast payments), the legal department (understandable contracts), the compliance department (enabling collaboration with patients or patient organisations) should also be patient-centric.

4 Metrics

Measuring the progress is vital to reach the desired patient centric culture. All of the above mentioned tools or initiatives could be translated into metrics.

Some suggestions for goals, KPIs or CSFs:

- Each manager/head of department needs to talk to at least five (for example) patients a year.
- Reception needs to know how to respond when patients contact them.
- Patient centricity criteria are included in employee evaluation
 - Score on those criteria, for example averages per department
- Number of questions received directly from patients in the call centre.
 - What kind of questions?
 - Do patients know that they can contact you directly?
- Number of questions from patient organisations in the call centre.
- Actions taken as a result of these patient questions.
- Measure where patients are involved throughout the product/service lifecycle
 - Study: Design, Recruitment, Execution, Results
 - Marketing
 - Product issue management
 - End-of-life management
- No projects are started without involving patients or evaluating the patient centricity
 - Numbers of projects with patient involvement
 - Number of projects with patient centricity score
- Patient satisfaction about involvement in project (contact, contract, felt listened to, impact of input...)

At the end of this document is a list of patient-centric quality indicators, which are focused on health care institutions, but they could serve as inspiration. Several consultancies offer patient centricity analyses or projects to improve patient centricity. They have other, proprietary, indicators.

5 Patient organisation-initiated actions

Patient organisations should take initiatives to collaborate with industry. Even actions that are not directly related to establishing a patient-centric culture will improve the perception of and the trust in patient organisations in the industry and thus increase the patient-centricity.

Industry partners are open to initiatives from the patient organisations, so they should not be afraid to propose projects and bring several companies to the table to launch pre-competitive projects.

Some suggestions:

- Provide real examples of how patient experts or patient organisations have played a leading role in enabling change in care.
- Take the lead in non-brand related initiatives on which the companies can step in to sponsor. For example a patient information project to avoid double materials for the same topics by different companies
- Proactively share patient concerns
- Bring all parties (industry, hospitals, government...) to the table in order to harmonise and centralise the information available to patients
- Professionalise the patient organisation
- Ask for feedback after each collaboration with a company. Patient Expert Center created a template survey: <https://form.jotform.com/240593219286361>
- Organise regular surveys to measure the patient centricity of companies. After each project, or on a (bi-)yearly basis.

Patient Centricity survey - examples of questions:

- What is your general satisfaction about the collaboration with the company?
 - Score 1 to 5
- Which aspects of the collaboration could still be improved?
 - Timelines
 - Reachability of the company
 - Communication/language
 - Relevance of the project(s) for the patient organisation
 - Other
- What would be the impact of this project (these projects) on the patients?
 - Score 1 to 5
- How well is the company aligned with the needs of the patients?
 - Score 1 to 5
- Would you recommend collaborating with the company to other patient organisations?
 - Score 1 to 5

6 Challenges

Issues to install and maintain a patient-centric culture could rise. Some are mentioned below with suggestions for solutions:

- Ensuring that **time and budget are structurally allocated** to discussing patient needs/patient experiences. This is connected to increasing understanding on the patients' experiences across all departments. It is possible that when the organisation's financial performance is under pressure, the patient-centric culture loses importance.
 - Involve leadership first
 - Highlight the positive business impact of patient involvement; in other sectors, entire companies have been set up just to identify customer needs.
- Even when doing many patient-centric projects it can be difficult to **show** how these projects have a **direct positive impact** on patients (not only on HCPs/healthcare system as a whole)
 - Patient Organisations should be involved in measuring the impact on patients
- A patient centric culture is **not installed forever**. It requires constant attention, especially when with newcomers.
 - Suggestions in 'maintain' (patient day, individual patient meetings for leadership, patient testimonials...)
- It is hard to have everybody **consider patients as equal** stakeholder; Lack of recognition/bad perception of Patient Advisory Groups by Govt/payer/HCP resonates in organisations.
 - Refer to shared decision making in clinical practice. HCPs increasingly consider the patient as an equal stakeholder in making treatment decisions.
 - Quick wins, good examples of collaborations with patient organisations.
 - Form coalition of the willing

7 Inspiration

In literature¹ several PC-QIs (Patient-Centred Quality Indicators) are mentioned. Although those are mainly focused on caregivers or hospitals, they can inspire to create industry metrics.

Type of indicator	Domain	PCC indicators (n=25)
Structure	Creating a patient-centred care (PCC) culture	<ul style="list-style-type: none"> • An induction programme is in place which promotes the philosophy of care.²² • % of PHC organisations who currently have processes to involve community input for planning the organisation’s services (eg, advisory committees and focus groups).²¹ • Clear policies are in place on how services are offered to patients.²¹
	Supporting a workforce committed to PCC	<ul style="list-style-type: none"> • Percent of nurses attending education sessions (orientation and organisation professional development opportunities) on client-centred care. • Percent of non-nursing staff attending education sessions (orientation and organisation professional development opportunities) on client-centred care.
Process	Cultivating communication	<ul style="list-style-type: none"> • Percent of patients with access to an online HER (a) by region and (b) by practice. • Proportion of service users who stated that the district nurse provided health advice or information about his/her condition. • Proportion of service users who stated that they were involved as much as they wanted to be in decisions about their care and treatment.
	Respectful and compassionate care	<ul style="list-style-type: none"> • Proportion of service users who stated that their district nurse treated them with respect and dignity. • Percent of inpatients who said they were always treated with respect and dignity while in hospital/primary care.
	Engaging patients in managing their care	<ul style="list-style-type: none"> • Percent of PHC clients/patients, 18 years and older, with a chronic condition(s), who actively participated in the development of a treatment plan with their PHC provider over the past 12 months.

¹ Santana MJ, Ahmed S, Lorenzetti D, Jolley RJ, Manalili K, Zelinsky S, Quan H, Lu M. Measuring patient-centred system performance: a scoping review of patient-centred care quality indicators. *BMJ Open*. 2019 Jan 7;9(1):e023596. doi: 10.1136/bmjopen-2018-023596. PMID: 30617101; PMCID: PMC6326310.

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Type of indicator	Domain	PCC indicators (n=25)
		<ul style="list-style-type: none"> • Percent of hospital patients who said they had been sufficiently involved in decisions about their care as much as they wanted to be. • Percent of nurses self-reporting: adequate assessment of a client’s perceived needs for care, adequate assessment of a client’s goals for care, adequate documentation of a client’s personal goals for care, sharing client’s concerns/choices with other members of the healthcare team, discharge teaching guided by the client’s goals for managing their care at home.
	Integration of care	<ul style="list-style-type: none"> • Percent of hospital patients taking medicines home after discharge who were told completely about the purposes of the medicine in a way they could understand.
	Access to care	<ul style="list-style-type: none"> • Percentage of patients who can get all diagnostic work ordered by their primary care doctor done the same day in the same location (excluding certain high-technology procedures such as CT and MRI). • Percentage of out-patients seen within 13 weeks of GP referral. • Percentage of those on waiting list waiting 12 months or more. • Proportion of service users who were able to contact a district nurse when needed, including outside of normal working hours. • The percentage of patients who, in the appropriate national survey, indicate that they were able to obtain a consultation with a GP or appropriate healthcare professional within two working days (NHS Confederation, UK). • Percentage of PHC clients/patients, 18 years and older, with a chronic condition(s), who had sufficient time in most visits to confide their health-related feelings, fears and concerns to their PHC provider.
Outcome	Patient-reported experiences	<ul style="list-style-type: none"> • Proportion of service users who stated that the district nurse had all the necessary information about the service user and his/her health needs. • Proportion of service users who stated that the district nurse had all the equipment and dressings needed. • Proportion of service users who stated that the district nurse was knowledgeable and competent. • Proportion of service users who rated the district nurse service as very good or excellent.

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Type of indicator	Domain	PCC indicators (n=25)
		<ul style="list-style-type: none"> Proportion of children whose parents routinely received all aspects of family-centred care (child and adolescent health measurement initiative).

Table 1: examples of PC-QIs

GP: general practitioner; HER: health electronic record; NHS: National Health Service; PCC: patient-centred care; PC-QIs: patient-centred quality indicators; PHC: primary healthcare.